

Fred Hutchinson Cancer Center

Consent to take part in a research study:

Development of Measures to Screen for Financial Hardship in Alzheimer's Disease and Dementia

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Study Phone: 206-667-7372

Important things to know about this study.

You are invited to participate in a research study. The purpose of this research is to describe the experience of financial hardship in Alzheimer's Disease. We also hope to improve screening for financial hardship.

People who agree to join the study will be asked to complete one interview about their experience of financial hardship after Alzheimer's Disease diagnosis. The interview will be about 60 minutes. Interviews can be by phone, in-person or virtually, according to your preference. Interviews will be recorded solely for research purposes and securely stored to ensure confidentiality.

During the study, we may learn new information you need to know. For example, some information may affect your health or well-being. Other information may make you change your mind about being in this study. If we learn these kinds of information, we will tell you.

Following is a more complete description of this study. Please read this description carefully. You can ask any questions you want to help you decide whether to join the study. If you join this study, we will give you a signed copy of this form to keep for future reference.

We would like you to join this research study.

We are examining financial hardship in Alzheimer's Disease. Since you are a person with Alzheimer's Disease or a caregiver to someone who is, we would like to ask you to join this research study. You also must be 18 years of age or older and able to read and speak English or Spanish to be in this study. We will enroll up to 60 people.

What will happen in this study?

If you decide to join this study, we will ask you to complete a 60-minute interview about your financial experiences after Alzheimer's Disease diagnosis for you or those who are you taking care of. The interview will be audio or audio/video recorded. The recording ensures that we accurately capture what people tell us. All recordings will be securely stored, and strict confidentiality measures will be implemented to protect participants' privacy.

How long will I be in this study?

Your participation in this study will consist of a single session lasting approximately 60 minutes. We may contact you after the interview to make sure we accurately captured your experience. If you are thinking about dropping out of this study, please tell us. You may withdraw from the study at any time without any cost, penalty, or consequences to you. If you leave the study, your test results and information cannot be removed from the study records. The study results will be presented with no identifying information included, to ensure the protection of your privacy and confidentiality.

Risks of being in this study

The primary risk of participating in this study is a potential breach of confidentiality. However, we will implement strict security measures to protect your information and ensure that all data remains confidential. Additionally, you may experience temporary distress while answering certain questions. If at any point you feel uncomfortable, you may take a break, skip a question, or withdraw from the study without any consequences.

What are the benefits?

We do not know if this study will benefit participants. We hope the information we learn will help people with dementia in the future.

You have other choices besides this study.

Participation in this study is entirely voluntary. You do not have to join, and you are free to say yes or no without any impact on your regular medical care. Your regular medical care will not change.

There are no alternative procedures for this study, but you may choose not to participate without any consequences.

Protecting your Privacy as an Individual and the Confidentiality of Your Personal Information

Some individuals or organizations may need to review your research records for quality assurance or data analysis. They include:

- Researchers involved with this study, and those working with them.
- The National Institute on Aging (the sponsor of the study) and their agents.
- Institutional Review Boards (IRB), including the Fred Hutchinson Cancer Center IRB. An IRB is a group that reviews the study to protect your rights as a research participant.
- Fred Hutchinson Cancer Center.
- US National Institutes of Health, Office for Human Research Protections, Food and Drug Administration, and other agencies as required.

We will make every effort to keep your personal information confidential. However, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. For example, we are required to report certain sexually transmitted diseases and HIV infection. We also have to report suspected abuse or neglect of children and vulnerable adults. A court may order study information to be disclosed. Such cases are rare.

We will not use your personal information in any reports about this study, such as journal articles or presentations at scientific meetings. We may use quotes from the interviews but these will not have any information that could identify a particular person.

Will you pay me to be in this study?

You will receive a \$50 gift card for completing the interview. The gift card can be electronic or hardcopy. We will need an email address or physical mailing address to send you the gift card.

How much will this study cost me?

There are no extra costs for being in this study.

For more information

If you have questions or concerns about this study, you can talk to your doctor anytime. Other people you can talk to are listed below.

If you have questions about:	Call:
This study (including complaints and requests for information)	Salene MW Jones, PhD, MA. Ph: 206-667-6976 Diana Lowry, Project Manager, Ph: 206-667-7372
If you get sick or hurt in this study	Salene MW Jones, PhD, MA. Ph: 206-667-6976
Your rights as a research participant	206-667-5900 or email irodirector@fredhutch.org (Director of Institutional Review Office, Fred Hutchinson Cancer Center)

What will my information be used for?

Your information and answers will be used for this study. We will use this information to better understand financial hardship in Alzheimer's Disease. This information will help us better address financial hardship.

During this study, we do not expect any test results that would affect your care, so we do not plan to return results to you.

Will my information ever be use for future research?

Your information will not be used for any research other than this study.

Signature

Please sign below if you:

- have read this form (or had it read to you);
- had the opportunity to ask any questions you have;
- had the opportunity to discuss the research with the person obtaining consent; and
- agree to participate in this study.

Participant (age 18+):

Printed Name

Signature

Date