UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: *Evaluating the Effectiveness of an Online Small-Group Self-Management Workshop for Rural Caregivers of Individuals with Alzheimer's Disease and Related Dementias*

This is a research study to see if an online workshop, Building Better Caregivers, improves the well-being of caregivers of people with dementia or memory problems (for example, Alzheimer's disease). The study's principal researcher is Veronica Yank, MD, from the UCSF Department of Medicine. You are being asked to take part in this study because you are a caregiver of a person with dementia or memory problems.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

Why is this study being done?

The purpose of this study is to learn whether a 6-week online self-management and skills-building workshop called Building Better Caregivers improves the well-being of caregivers of people with dementia or memory problems (for example, Alzheimer's disease) living in rural settings throughout the United States.

Who is paying for this study?

The National Institute on Aging is paying for the costs of this study, including part of the salary for Dr. Yank.

How many people will take part in this study?

About 678 people throughout the United States will take part in this study.

What will happen if I take part in this research study?

If you are eligible for the study and agree, then the following procedures will occur:

- **Complete the first online survey:** You will complete the first online survey that lasts about 20-40 minutes or you may complete it by mail or phone if you prefer. You will be asked about your feelings, your caregiver experiences, and questions regarding your health and the health of the person with dementia or memory problems.
- **Be assigned to a research group:** You will then be assigned to one of two groups. This will be determined by chance (like flipping a coin). You will be assigned to the workshop group or the attention control group. If you are assigned to the *Building Better Caregivers* workshop group, you will begin the program immediately. If you are assigned to the attention control group, you will begin the *Building Better Caregivers* workshop when the study is over.
- **The Building Better Caregivers Workshop Group:** When you begin the workshop (either now or when the study is over) the following will take place:
  - You will participate in an online 6-week interactive workshop.
  - Workshops consist of small group or about 20-25 persons.

- Two peer co-facilitators (caregiver themselves) will guide workshop activities.
- You will learn self-management, social support, and topics that focus on caregiving skills.
- You will receive a workshop booklet.
- Each week, you will log on at least 2-3 times for a total time of approximately two hours.
- Your participation does not require "real time" attendance at pre-determined times.
- Workshop interactions may be recorded via screen shots on the workshop platform to ensure quality of standard workshop delivery.

❖ **The Attention Control Group:** If you are assigned to the attention control group the following will take place:
- You will receive a caregiver handbook on tips and resources.
- You will receive two brief phone calls of 15-30 minutes apiece from research staff.
- Phone calls may be recorded to ensure quality of standard phone call delivery.
- You will be offered the Building Better Caregivers online workshop after the study is over, if you desire.

❖ **Complete three additional online surveys:** You will complete three additional survey interviews. One interview will be in 1.5 months from now, another in 6 months and the last one will be in 12 months from now. You may also complete these surveys by mail or phone if you prefer. Each of these interviews should take about 20-30 minutes.

How long will I be in the study?

Your participation in the study will last about 12 months. We estimate that participating in the Building Better Caregivers workshop and study will take about 2 to 14 hours total including the surveys, telephone calls (for control group), and workshop participation, depending on your group assignment.

Can I stop being in the study?

Yes. You can decide to stop being in the study at any time. Just tell the study researcher or staff person as soon as possible if you wish to stop being in the study.

The study researcher can end your participation in the study if the study researcher decides that your participation is not in your best interest, if you do not follow the study rules, or if the study is stopped before the allotted time.

What side effects or risks can I expect from being in the study?

- Potential risks for taking part in this study may make you feel uncomfortable, upset or other emotional responses as a result of answering survey questions or during the interview, but you can refuse to answer or stop the interview at any time.
- You may end any telephone calls or workshop participation at any time if talking about your caregiving experiences makes you feel uncomfortable or sad.
- There is also a risk of loss of confidentiality. We will take steps to protect your privacy, however we cannot guarantee total privacy.
- We know that caregivers have a lot of stress in their lives. You will be given appropriate resources and psychological referrals if necessary or requested. You should contact the Project Physician at (415) 476-9654, if you desire. You can also contact the Alzheimer's

Association helpline at 1-800-272-3900 which is separate from the study or go to their website for more resources at www.alz.org.
- For more information about risks and side effects, ask one of the researcher team staff.

Are there benefits to taking part in the study?

There may be no direct benefit to you from participating in this study. The possible benefit of your participation in this study is that you will receive an interactive workshop and online support from another caregiver. These include support from other caregivers, training on how to manage stress, information on caregiving skills and resources, and a workbook to keep. We also hope the information learned from this study will help us potentially spread such workshops to caregivers throughout rural America.

What other choices do I have if I do not take part in this study?

Your other choice is to not participate in the study and refuse to participate in the online workshop. If you decide not to participate in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your care from our institution the way you usually do.

How will my information be used?

Researchers will use your information to conduct this study. Once the study is done using your information, we may share them with other researchers so they can use them for other studies in the future. We will not share your name or any other personal information that would let the researchers know who you are. We will not ask you for additional permission to share this de-identified information.

Will information about me be kept private?

Yes. Participation in research may cause a loss of privacy, but we will do our best to make sure that the personal information gathered for this study is kept as confidential as possible. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Authorized representatives from the following organizations may review your research data for the purpose of monitoring or managing the conduct of this study:
- Representatives of the National Institutes of Health
- Representatives of the University of California
- Representative of Canary Health (hosts the online workshop platform)

Are there any costs to me for taking part in this study?

None. You will not be charged for taking part in this study.

Will I be paid for taking part in this study?

You will be paid up to a total of $80 for taking part in this study as follows:

- $20 in cash for the 1st baseline 20-40-minute online survey.

- $20 in cash for the 2nd follow-up 20-30-minute online survey (in 1.5-months).
- $20 in cash for the 3rd follow-up 20-30-minute online survey (in 6-months).
- $20 in cash for the last follow-up 20-30-minute online survey (in 12-months).

What are my rights if I take part in this study?

Your participation in this study is voluntary. Even if you decide to participate, you may leave the study at any time. No matter what decision you make, there will be no penalty to you. You will not lose any of your regular health care benefits, and you can continue to get your care from your regular health care provider the way you usually do.

Who can answer my questions about the study?

You can talk to the researcher(s) about questions, concerns, or complaints you have about this study. Contact the researcher(s): Veronica Yank at (415) 476-9654 or Jasmine Santoyo-Olsson (project coordinator) toll-free at 1-833-634-0603.

If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Institutional Review Board at 415-476-1814.

CONSENT

You can print a copy of this consent form to keep or we can mail you a copy.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

Date	Participant's Signature for Consent
Date	Person Obtaining Consent