INDIANA UNIVERSITY/CARE ALLIANCE IRELAND/ THE ALZHEIMER SOCIETY OF IRELAND

INFORMED CONSENT STATEMENT

for

Friendsourcing Ireland (Protocol Number 19027773321)

You are invited to participate in a research study of online family caregiver social support. You were selected as a participant because you are a caregiver of a person with Dementia, as well as a Facebook user**.** Please read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. David Wilkerson, Indiana University School of Social Work, Dr. Daniel Bateman, Indiana University School of Medicine, Liam O'Sullivan, NQSW, MA, Care Alliance Ireland, and Fergus Timmons, The Alzheimer Society of Ireland. It is funded by the Government of Ireland under the Dormant Accounts Fund – Carers Measure.

STUDY PURPOSE

Caregivers' social and support networks can shrink when caregiving role demands increase. The purpose of this study is to help caregivers cope with shrinking social support through an online intervention called Friendsourcing. The intervention provides caregivers practice and support in the use of social media to develop their social and support networks online. It is conducted in professionally moderated, private Facebook support groups. The intervention has been shown in previous research to have the potential to improve coping, reduce burden, and reduce perceived stress.

NUMBER OF PEOPLE TAKING PART IN THE STUDY

If you agree to participate, you will be one of approximately 80 participants, all of whom live in the Republic of Ireland and are currently caring for someone with dementia. The study will take place with 4 separate groups of no less than12 and no more than 20 other participants who are caregivers of a person with Alzheimer's disease.

PROCEDURES FOR THE STUDY

If you agree to be in the study, you will do the following things:

1. Completing Surveys: Study surveys ask questions about you, your caregiving experiences, and social media use. Caregiving questions ask about social support, caregiving challenges, dementia symptoms that you manage, and your experiences in coping with caregiving tasks. The time needed for completing surveys is 20-30 minutes.
2. Weekly Activities: Participants who consent will participate in a facilitated online, caregiver discussion group conducted in a closed and private Facebook group that is only used for this research. You can read and type messages at times that are most convenient for you. Group discussions will be structured so that you and your group members will decide on questions that members want answered concerning informational and emotional support. Groups will troubleshoot answers received and decide which answers are most meaningful. Participants will also learn most effective methods for using social media to support caregiving. Participation in discussion groups will last for 8 weeks from beginning to end.
3. Use of Facebook Newsfeeds for Social Microvolunteering: The questions selected by your group will be posted to a public-facing Facebook page for you and your group members to comment. Commenting will allow your Facebook friends to see the question and participate to help answer questions. Providing Facebook friends with the opportunity to help answer questions is called social microvolunteering. Their answers and comments are posted in the closed Facebook support group.

4. Ending Participation: At the end of your group discussions, you will be invited to complete three activities that will be used to measure your caregiving experiences related to group participation. These include:
    a. Repeating and completing of the surveys you completed before beginning discussions.
    b. One to two weeks following group participation you will be invited to join a focus group discussion about your experiences in the program. These would include your liking or disliking of different aspects of your participation, including your experiences in the caregiver discussion group. The focus group will meet over the phone for 90 minutes.
    c. Approximately 3-4 months following group participation you will receive a final survey by email that asks about what aspects of the study continue to be meaningful for your caregiving role.

RISKS OF CONSENTING TO STUDY AND COMPLETING INITIAL QUALIFICATION FOR STUDY

If you agree to participate, you will be asked several questions to help decide if you should continue in the study. You could experience distress if your answer to any of these questions excludes you from participating. To minimize distress related to these questions, please review the questions are listed below.

Participants will be invited if they agree to all the following:

- Participant is 18 years or older and living in the Republic of Ireland
- Participant can read, comprehend, and write in the English language.
- Participant is an unpaid caregiver of an individual with dementia
- Participant provides at least 8 hours of caregiving for person with dementia per week.
- Participant has a Facebook account.
- Participant has at least 20 friends in their Facebook social network
- Participant posts on Facebook on average at least once per week for the past month.
- Participant has ready access to the Internet.
- Participant agrees to give their informed consent to participate in this research.
- Participant has had no mental health hospitalisation in the past year.
- Participant has made no suicide attempt in the past year

RISKS OF TAKING PART IN THE STUDY

While in the study, the risks are:

1. When completing surveys, you may feel discomfort with questions that ask about your caregiver experiences for receiving social support, dealing with challenges and feeling in control of caregiving. If you feel discomfort you can tell the researcher that you do not want to answer a particular question. You may also skip answering a question you feel uncomfortable with.
2. When participating in the Facebook group discussions, you may feel discomfort when sharing your caregiving experiences and seeking answers to your questions about informational and emotional support. If you feel discomfort you can tell the researcher, or you can decide not to share information that makes you feel uncomfortable. Groups will be observed by a member of the research team for signs of discomfort.
3. In addition, all communications in the private Facebook support group are confidential and no information discussed in the group should be discussed outside of the group. –Even so, there remains the risk that other group members could intentionally or unintentionally share your private information outside the group. Should public comments appear in posts that identify any personally identifying individual information (either directly and or indirectly) - such comments will be removed by one of the Facebook page administrators/moderators. In addition, the person who posted the comment will be contacted directly, asking them to refrain from posting such identifying comments again.

In addition, the purpose of the group is to support caregivers. Any abusive language will can be handled as follows: Further communications will be blocked until the person in question discusses their abusive language with a moderator and agrees to refrain from further such behavior. In addition, communications can also be set so they must be approved by a moderator before they appear in the group.

4. You group will work to agree on a weekly question to share with your Facebook friends about either informational of emotional support. This question will be posted on the program's public-facing page. When you follow this page and comment on the question, your Facebook friends will be able to see the question and have opportunity to respond. If you decide to comment you may receive comments about caregiving from your Facebook friends that could cause you to feel discomfort because Facebook comments are publicly viewable. However, you can decide not to comment, and your Facebook friends will not see the question. In addition, if you choose to comment, it does not need to include any personal information about your own caregiving experiences.

BENEFITS OF TAKING PART IN THE STUDY

The benefits to participation are based on the online nature of participation, and on the use of the research's social microvolunteering app:

1. The Friendsourcing program can potentially deliver your groups' questions to all group members' Facebook friends. In a 20-member group, your questions can reach 20 times the number of people that would be reached through your Facebook Newsfeed alone. Previous research with the program showed it can potentially result in very rapid and broad levels of informational, emotional support, and reduced burden, as well as stress.

ALTERNATIVES TO TAKING PART IN THE STUDY

An alternative to participating in this study that might be advantageous for communicating and receiving support includes joining any of several Facebook groups that are dedicated to the challenges of dementia.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential and any survey questions that you answer will be stored in a secure database that is password protected in a secure server at Indiana University. However, we cannot guarantee absolute confidentiality. Because this study is being conducted in collaboration between U.S. and Republic of Ireland researchers, in the U.S. your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and databases in which results may be stored.

Because the U.S. researchers are providing secure database for storing information, U.S. organizations may inspect and/or copy your research records for quality assurance. Also, data analysis will include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP).

WILL MY INFORMATION BE USED FOR RESEARCH IN THE FUTURE?

Information for this study may be used for future research studies or shared with other researchers for future research. If this happens, information which could identify you will be removed before any information is shared. Since identifying information will be removed, we will not ask for your additional consent.

COSTS

There are no financial costs associated with taking part in this study.

PAYMENT

You will receive payment for taking part in this study. Participants will receive payment for their time to complete online surveys. Participants will receive STG£10 vouchers after completion of pre-program survey completion and STG £10 vouchers for post-program survey completions.

FINANCIAL INTEREST DISCLOSURE

None of the individuals involved in this research will benefit financially from this study. If you would like more information, please ask the researchers or study staff.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the study researchers at any time through friendsourcing@carealliance.ie or call Care Alliance Ireland at 085-720 1184. If you cannot reach the researcher during regular business hours (i.e., 9 a.m. to 5 p.m.), please call the Care Alliance Ireland project manager at 087-207-3265, or the IU Human Subjects Office at 00-1-317-278-3458.

VOLUNTARY NATURE OF THIS STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with any entity of Indiana University, Care Alliance Ireland, or the Alzheimer Society of Ireland.

If you begin the group but circumstances prevent you from participating, please contact the study researchers at friendsourcing@carealliance.ie

SUBJECT’S (PARTICIPANT'S) CONSENT

After reading this Statement of Informed Consent, if you choose to participate, you are asked to type your name on our online survey and then click “YES” if you agree to take part in the study.