

Study Title: A Mindful Community for People with ALS and their Primary Caregivers

ALSA Grant 21-MALS-572

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This study aims to find out if an online mindfulness training program combined with a social forum can help people with ALS and their caregivers with their quality of life. The research consists of a one-month online training program followed by a six-month online sharing program, and if desired, further engagement after that. The primary aims of this project are two-fold: to develop a “mindful” online community of people with ALS and their caregivers, and to test its helpfulness in improving quality of life. These aims look closely at the feasibility and psychological effects of a dual program to provide an online “mindfulness-without-meditation” program followed by a social mindful community to interact with each other. The study is built upon previous research by this study team testing an online mindfulness intervention for people with ALS and their caregivers, as well as research about the positive impact that mindfulness has on the ALS community

Participants will be asked to review the consent form and provide informed consent and will then be randomly assigned to one of the two study groups. Each group will have a different version of a training program, with some overlap, that will last for three weeks. Participants will then be asked to participate in a three-week online mindfulness-based program. After program completion participants will be asked to join an online community to interact with others from the training program. The program and community will incorporate activities that that can be completed in less than 10 minutes per day at home.

During this time, there will be five (5) online assessments: before beginning the mindfulness program; right after the program; and at 1, 3 and 6 months after joining the mindful community. Each of these assessments takes less than 20 minutes. There are no in-office visits for this study.

A description of this research study will be available on <http://www.ClinicalTrials.gov>. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

If you have questions please contact the research team members: Dr. Deborah Phillips, dphillips@fas.harvard.edu, Dr. Francesco Pagnini, Francesco.pagnini@unicatt.it, or Dr. Ellen Langer, langer@wjh.harvard.edu.

This research has been reviewed and approved by the Harvard University Area Institutional Review Board (“IRB”), IRB20-0629.



Online Mindfulness Learning and Social Sharing Program
for People with ALS and their Caregivers
New Study!

Click this Link to see if you are eligible here! [ALS Consent and Eligibility Link](#) or Scan this QR Code:



What is it?

This is a research study conducted by researchers in Harvard University's Psychology Department funded by a grant by the ALS Association (21-MALS-572). It is designed to determine if an online mindfulness program followed by a structured social sharing interaction can impact the quality of life of people with ALS and their caregivers. The online mindfulness program will take 5-20 minutes of your time on most days over a 3-week period. You can access the mindfulness program's website from your computer or mobile device.

Who can join?

Participants must have been diagnosed with amyotrophic lateral sclerosis (ALS) or be a caregiver for someone with ALS.

What will happen if I decide to join?

You will be assigned to one of two groups – each group will focus on two different training programs with mindfulness components. Both groups will complete online questionnaires at the beginning of the study and again at 3 weeks, 3 months, and 6 months. A small monetary payment is provided to participants in both groups.

How many people will participate?

Approximately 300 people including people with ALS and their caregivers will take part in this research study.

Will there be any participant compensation?

Yes, this study provides for compensation in the form of a lottery raffle. There will be 2 \$50.00 Amazon coupons provided as incentive; using the estimated 320 total participants there will be a 6.3% chance of winning a coupon. All participants are eligible by completing the 3-week follow up, at which time you can enter the raffle.

If you are interested in participating or if you have questions about the study, please contact Dr. Deborah Phillips (dphillips@fas.harvard.edu) or Dr. Francesco Pagnini (francesco.pagnini@unicatt.it) for further information. This study has been approved by the Harvard University IRB (IRB20-0629).