

# Minds Together:

## Participant Information Statement

Thank you for your interest in this research. You are invited to participate in this pilot study for family and friends caring for a person who has attempted suicide.

### **What is the purpose of this study?**

We have recently developed a new online program for family and friends supporting someone in their life who has attempted suicide. The purpose of this study is to evaluate whether caregivers will engage with and benefit from the program and online social support forum.

### **Who is conducting the study?**

This study is being conducted by Andrew McMahon as part of his PhD research. Andrew is supervised by Dr Sally Fitzpatrick, Professor Myfanwy Maple, and Professor Francis Kay-Lambkin. The study is funded by Suicide Prevention Australia.

### **Who can participate in this study?**

To participate in this pilot study, you must be able to answer “yes” to each of the following questions:

- Are you caring for a family member or friend who has attempted suicide?
- Is the person you are caring for over 18 years of age?
- Are you currently living in Australia?
- Are you 18 years of age or older?
- Are you comfortable reading and writing in English?
- Do you have access to a computer, tablet or phone with a reliable internet connection, and are you comfortable using web-based programs?
- Do you understand that this program is not aimed at family and friends currently experiencing high levels of distress and require more immediate one-on-one support?
- Do you agree to access the online program and complete three short questionnaires?

### **What will I be asked to do?**

**Voluntary Participation** - Please understand that your involvement in this study is voluntary, and we respect your right to withdraw from the study at any time. You may discontinue the survey or the online programs at any time without consequence, and you do not need to provide any explanation if you decide not to participate or withdraw at any time.

**Screening Survey and Consent** – If you are interested in participating in this study, you will be asked to complete a brief screening survey, to determine whether this study is suitable for you. You will also be asked to read and understand this Participant Information Statement. You will then be asked nine (9) consent-based questions and asked to provide your **consent to participate** in the pilot study, by selecting a yes/no option.

**Initial Survey** - After you provide your consent to participate in this study, you will be asked to complete an online-based **pre-program survey**. You will be asked about your experience of caring for a family member or friend who has attempted suicide and the impact this has had on you. You will also be asked about your mental health and thoughts of suicide. Each survey should take approximately **10 minutes** to complete. You can change answers on any survey page until the survey is completed.

**Randomisation** - Once this survey is completed, you will be randomly allocated to either:

- **The program group:** a group that has access to an online support program for an eight (8) week period.
- **The program + social forum group:** a group that has access to an online support program for an eight (8) week period, with additional access to an online social support forum.

**Online Program** - Following your random allocation, both groups will be asked to complete, **two (2) core modules, and six (6) optional in-depth topics** over an **eight (8) week period**. We expect each core module to take between **1-2 hours** to complete, and each optional mini-module to take 15 – 30 mins. The program will be delivered online through a mixed media format including text, short videos, infographics, and short podcasts. The modules will contain case studies, activities, worksheets, and reflective questions that you can answer. No grade will be given for any of the exercises. The modules address the following topics:

- **Module 1 – Supporting your family member or friend** - information about suicidal distress, mental health and exploration of the caring journey for the caregiver and the person they support.
- **Module 2 – Looking after yourself** - looking further at the caring journey and exploring caregiver wellbeing and self-care.
- **Mini-Modules** –will go in to further depth on topics discussed in Modules 1 and 2, including talking about suicide, stigma, self-care, communication, safety plans, feelings and hypervigilance.

**Online Social Support Forum** - If you are randomised to the program + social forum group, you will also have access to an online social support forum hosted by SANE Australia. The site is similar to a *Facebook group* (although it will be anonymous) and will provide an opportunity for you to share your story, thoughts, questions and messages of support with other carers. Only participants allocated to this condition will have access to the social forum. The site will be moderated and all inappropriate posts will be removed. Support from a clinical psychologist will also be available. Participants can contribute to this site as much or as little as they like, however, there is no requirement to post if you do not wish. It is recommended that they log in at least **once per week**. The first time participants log into the online social support forum, you will be asked to read and agree to the SANE Forum's [Terms & Conditions](#), [Privacy](#) and [Community Guidelines](#).

**Reminder Emails** – While you are completing the online program (and social forum for some participants) you will receive a **weekly reminder email**, recapping how to access the program (and forum for some participants).

**Post-program and Follow-Up Surveys** - After completing the online modules (and social forum access for some participants), you will then be asked to complete an online-based **post-program survey**. Surveys are expected to take about **10 minutes** and will include questions pertaining to: your health and wellbeing, your experiences caring (including during the COVID Pandemic), and your experience using the online program (and social forum for some participants). You will then be contacted via email 12 weeks after the access period to complete a **follow-up survey**. This survey will ask about your health and wellbeing.

**Optional Follow-Up Interview and Consent** - Upon completion of the three (3) month follow-up survey, caregivers in both conditions will be invited to participate in an **optional** phone-based **interview** seeking further feedback on both the Program and the Forum (depending on your assigned condition) as well as your experiences as a caregiver. If you agree to participate in the voluntary follow-up interview, you will be asked seven (7) consent-based questions and then asked to **provide your verbal**

**consent** to participate in the interview. The interview will take approximately **20-30 minutes** and can be stopped at any time. The interview will be recorded and participants will have the option of reviewing the transcribed record of the interview. At the conclusion of the interview, a participant mental health check will be completed and a further follow-up check-in will also be offered.

## How will your privacy be protected?

The research team will adhere to the following protocol to ensure participant privacy and confidentiality is maintained throughout the research:

- All information from this study (program activities, forum posts, survey results and voluntary interviews) will be kept strictly confidential and will be stored on a password-protected computer. The person coordinating the project, and a research team involving people from Everymind will have access to your information. The online program will be accessed through Everymind's *Minds Together* digital portal and will follow the [Everymind Privacy Policy](#).
- Participant details will be stored in a separate file to the survey data collected.
- Any information that is published will be grouped information only, so participants will not be personally identifiable in any publications or reports based on the research.
- Your data will be collected and managed using REDCap electronic data capture tools hosted at HMRI. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. You can learn more [here](#). ([projectredcap.org](http://projectredcap.org))
- Data will be stored securely for a minimum period of 15 years from completion of the research and will be stored in accordance with the HNELHD's Data Storage Policy
- SANE Australia Forum Data will be stored following their [Privacy Policy](#).

## How will the results be reported?

The results will primarily be used to compare caregiver outcomes across the two study conditions (program + social forum). A summary of results will be made available to you, if you indicate that you would like to receive these results as part of the screening survey. Information provided in online program activities or posted on the social forum may be summarised into de-identified quotes and summaries for submission to peer-reviewed scientific journals, presented at academic conferences, and/or utilised in future research. Similarly, metadata from the program and social forum also be compiled into a de-identified overview of the time participants spent and their level of engagement on the platforms and in the surveys for use in publications, presentations and future research.

## Upsetting issues

If undertaking the surveys or interventions brings up difficult emotions for you, you may wish to contact:

- SANE Australia Help Line on **1800 187 263** (10 am to 10 pm Monday to Friday),
- Lifeline on **13 11 14** for free online and telephone counselling, available 24 hours a day, seven (7) days a week
- Suicide Call Back Service on **1300 659 467** for free online and telephone counselling, available 24 hours a day, seven (7) days a week
- QLife on **1800 187 263** - National LGBTI peer support and referral service, with free phone and web chat services available from 3PM - 12AM, 7-days a week.
- 13YARN – **13 92 76** - Free, 24-hour confidential crisis support run by Aboriginal and Torres Strait Islander Peoples, available 24 hours a day, seven (7) days a week.

## Research team

This research is conducted by Everymind and the University of Newcastle and funded by the Suicide Prevention Australia Research Fund. The six (6) researchers listed below are involved in the project design, data collection and analysis:

- Dr Sally Fitzpatrick, Program Manager, Everymind
- Andrew McMahon, PhD Student, University of Newcastle / Everymind
- Professor Frances Kay-Lambkin, University of Newcastle
- Yohana Franklin, Project Lead, Everymind
- Dr Philippa Ditton-Phare, Project Lead, Everymind
- Dr Jose Cuenca, Research Lead, Everymind

## Ethics

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2022/ETH02126.

## Governance

The conduct of this research has been authorised by the Hunter New England Local Health District to be conducted at the Everymind site.

## Complaints about this research:

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: HNELHD-ResearchOffice@health.nsw.gov.au and quote the reference number: 2022/ETH02126.

## IN SUMMARY – What you will be asked to do?

- Participation is voluntary – you may withdraw at any time
- Complete a pre-program survey (~10 mins)
- Complete two core modules, and up to eight optional mini-modules over eight (8) weeks ( ~1 – 2 hours for each core module, and 15-30 mins for each optional mini-module)
- Log into Online Social Support Forum once per week (If allocated to this group)
- Receive weekly reminder emails
- Complete a post program survey (~10 mins)
- Complete a follow-up survey (~10 mins)
- Participate in an optional follow-up phone/zoom interview (~20/30 mins)