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Participant Information Sheet

Proxy Resident

Project Title: An evaluation of RBC Enrich for building connection with people with dementia

Project Summary: You are invited to provide consent for your family member (or the person you are the Registered Supporter for) to participate in a research study being conducted by Dr Celia Harris, Associate Professor at the MARCS Institute for Brain, Behaviour and Development, Western Sydney University in collaboration with the Whiddon. This research is evaluating an 18-month program called "RBC Enrich" involving residents with dementia and staff, family and volunteers. RBC Enrich aligns with the Memory Bridge model of care, founded by Michael Verde, and Whiddon's Relationship Based Care approach and aims to address the emotional isolation of people with dementia by fostering meaningful, empathetic connections between individuals with and without dementia. The model is built around educational experiences, such as workshops and coaching for staff and volunteers, that encourage participants to form one-to-one, meaningful relationships with residents and learn from each other about the nature of communication and connection beyond words.

We are conducting an independent research program to study RBC Enrich program and its outcomes. You have been invited to take part in this research as you are one of the 3 Whiddon Homes where RBC Enrich is being conducted, primarily for residents and staff. Family and volunteer caregivers may also be invited to participate.

How is the study being paid for? This research is funded by the Whiddon Group.

What will my family member be asked to do? This study's evaluation of Whiddon's RBC Enrich program requires your family member (or the person you are the Registered Supporter for) to participate at four time points: before, during and after the RBC Enrich 18-month trial. You will be asked to consent to a Whiddon staff member completing observational wellbeing measures (examining quality of life, and mood) at four time points (before, during and after the implementation of the Memory Bridge program). You will also be asked to consent to this information, and general demographic information data (e.g., dementia diagnosis, gender, age, length of time residing in Whiddon) to be shared confidentially and securely by Whiddon to a member of the research team at Western Sydney University. In addition, you will be asked to consent to four x 15 minutes video or audio recordings (optional) between your family member (or the person you are the Registered Supporter for) and their caregiver (staff, volunteer or family member). These recordings will be obtained at four time points (before, during and after) the implementation of the 18-month RBC Enrich program.

How much time will my family member need to give? This study will not require any additional time outside of the time residents normally interact with staff, volunteers, or family members in their normal care routine.

What benefits will my family member (or the person I am the registered supporter for) and/or the broader community, receive for participating? We anticipate that engaging in the study will be an enjoyable and meaningful activity for residents. We will be collecting and reporting data and insights to enhance our understanding of the wellbeing needs of residents living with dementia, and to evaluate the ways in which Memory Bridge may be supporting them to enjoy social connections.

Will the study involve any risk or discomfort? If so, what will be done to rectify it? We do not expect that engaging in this study will involve any risk or discomfort. However, we acknowledge that living with dementia is not always easy. Understanding these challenges will help us to ensure that the RBC Enrich program is relevant to the realities of your experiences of people living with dementia in residential aged care contexts. Should your family member (or the person you are the Registered Supporter for) experience any discomfort you are able to discontinue their involvement in the program at any time without giving any reason and without any consequences. You can tell the person running the program if you would like them to withdraw. Also, members of the research team will check in regularly with residents, to ensure they are happy to participate. They will also look for signs of distress such as fidgeting, avoidance of eye contact, or vocalizations, and will discontinue when observed. If you observe your family member (or the person you are the Registered Supporter for) distressed as a result of their participation, or are concerned about your mood and wellbeing, you can raise your concerns with the nursing unit manager and/or Whiddon staff who will take appropriate action according to Whiddon policies and procedures.

How do you intend to publish or disseminate the results? It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission. For example, the questionnaires and transcripts from interviews will be given a participant number only. The name of your family member (the person you are the Registered Supporter for) and any identifying information is removed from the transcript and any other information obtained.

Will the data and information that I have provided be disposed of? Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time ie. 7 years.

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For example, other Western Sydney University researchers may analyse the video and/or audio recordings to examine different research questions around what makes good quality interactions in dementia care, that are beyond the scope of the current project. Also, the raw data could be accessed by other researchers through online research platforms, but this would not include video or audio recordings.

Can my family member withdraw from the study? Participation is entirely voluntary, and there is no obligation to be involved. If your family member (or the person you are the Registered Supporter for) do not want to participate you can withdraw consent for them at any time without giving reason by telling a member of the research team or Whiddon staff that you do not want them to be involved anymore. If you do choose to withdraw any information that you have provided will be deleted.

What if I require further information? Please contact Dr Celia Harris should you wish to discuss the research further before deciding whether to participate.

Email: celia.harris@westernsydney.edu.au

Privacy Notice. Western Sydney University staff and students conduct research that may require the collection of personal and/or health information from research participants. The University's Privacy Policy and Privacy Management Plan set out how the University collects, holds, uses and discloses personal or health information. Further details about the use and disclosure of this information can be found on the Privacy at Western Sydney webpage.

What if I have a complaint? If you have any complaints or reservations about the ethical conduct of this research, you may email the Ethics Committee through Research Services: humanethics@westernsydney.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree for your family member (or the person you are the Registered Supporter for) to participate in this study, you will be asked to sign the Proxy Consent Form. The information sheet is for you to keep, and the consent form will be retained by the research team.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H17037

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Explanation of Consent

What will happen to my information if I agree to it being used in other projects? Thank you for considering your family member (or the person you are the Registered Supporter for) participating in a university research project. The researchers are asking that you agree to supply your family member's (or the person you are the Registered Supporter for) information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects. This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area. You have been asked to agree to Extended consent.

What does this mean? When you give extended consent, you agree that the data of your family member (or the person you are the Registered Supporter for), as part of a larger dataset (the information collected for this study) can be re-used in projects that are:

- an extension of this project,
- closely related to this project,
- or in the same general area of this research.

The researchers will allow this data to be used by other researcher at Western Sydney University. For example, other Western Sydney University researchers in future studies may analyse the video and/or audio recordings to examine different research questions around what makes good quality interactions in dementia care, that are beyond the scope of the current project. Also, the raw data could be accessed by other researchers through online research platforms, but this would not include video or audio recordings. To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review. The researchers want to keep the data for 7 years for possible re-use. After this time the data will be securely destroyed. You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the National Statement on Ethical Conduct in Human Research – see Sections 2.2.14 - 2.2.18.

https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

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