University of the West of England
BRISTOL

PARTICIPANT INFORMATION SHEET

A feasibility study to test whether using past memories to increase psychological resources leads to better recall of information about dementia

We are inviting people who have recently been diagnosed with dementia to take part in our research study. Before you decide to take part, it is important for you to understand why we are doing this study.

Please take the time to read this information and discuss with friends and family if you wish.

Your participation in this study is entirely voluntary. Taking part in this study is separate from your treatment and care. Your treatment will not be affected in any way by deciding to take part or not. If you decide not to carry on with the study or want to withdraw you will be able to and this will not affect your treatment and care in anyway.

Why are we doing this research?

Our study, organised by researchers at the University of the West of England is funded by Alzheimer's Research UK.

This study follows on from two previous studies we have completed. Findings from the first study funded by the Alzheimer's Society suggest the way in which information is given about a diagnosis affects how well this information is remembered. The second study showed that recalling past memories can improve how people feel about themselves, for example increasing self-esteem. So in this study we are combining these two projects to see whether recalling a past memory beforehand leads to better recall of information about an illness.

What would taking part involve?

The study involves a number of tasks which will take, at the most, 45 minutes to complete. First we will ask you some questions about your mood. We will then ask you to remember an event from the past. At this point, we will record the experience you have described using a voice recorder. You will then complete a questionnaire after the task based on how you feel at that moment.

Next the researcher will read out a series of statements about an illness and you will be asked to remember as many of these as you can.

A researcher can come to your home or you can come into the clinic to take part, whichever is easiest for you.

What are the possible benefits of taking part?

You will be adding to scientific knowledge about dementia and how information about diagnosis is communicated. Without volunteers like you research of this kind would not be possible. Your participation and contribution is, therefore, invaluable.

What are the possible disadvantages of taking part?

We do not feel that there are many disadvantages to taking part. Some of the information in the memory tasks you might find upsetting. You might feel a bit tired after taking part. Please do let the researcher know how you are feeling and they will be able to support you. Should you feel distressed following your participation then you can contact Prof Rik Cheston, Chief Investigator of the project whose details are at the bottom of this sheet.

Who will be informed of my participation?

If you decide to take part in the study, copies of the consent form that you sign will be passed on to your direct care team to be included in your medical notes.

Who will have access to my medical records?

If you have been attending the RICE clinic, then members of the clinical team will have access to your medical notes in order to look at previous assessments that are directly related to this study. If, you have registered on the Join Dementia Register, then we will take this information from the statements that you made when you enrolled.

Who has funded this study?

This study has been funded by the Alzheimer's Research UK.

Who has approved this study?

The East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from the University of the West of England and Bath & North East Somerset Clinical Commissioning Group, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

In addition, this study has approval from the University Research Ethics Committee (UREC) at the University of the West of England.

What if there is a problem?

If you have a concern about any aspect of this study, in the first instance you should speak to the researcher who will do their best to deal with your concerns. You can also discuss further with the Chief Investigator, Prof Richard Cheston (0117-3288927).

If you are still not happy and wish to complain formally you should contact The Patient Advice and Liaison Service or Bath & North East Somerset Clinical Commissioning Group (01225-831800)

What will happen to my data?

All data collected during the study will be anonymised. This means that you will be given a participant number and all the data you provide will be linked to that number rather than to any information that could identify you such as your name, age or gender. A list linking your study number with your name will be kept by the researcher in a password-protected file, and will not be accessed by anyone else. Data collected as part of this study will be kept securely for a period of six years after the end of the study after which time it will be destroyed.

The results will be published in peer-reviewed journals. We may use anonymised direct quotations in study reports but you will not be able to be identified in any published results. If you decide you would like to be sent information then please let the researcher know. We can send you a summary of the results and/or a copy of published papers if you chose by completing the appropriate box on the consent form. In order to do this, the researcher will keep a secure record of your contact details (your name and address) and will send you the information once all data is collected and analysed after which your details will be deleted. The research team envisage this could be up to a year after the start of the study.

Further information

If you do decide to take part we will ask you to sign a consent form and we will give you a copy of this information sheet and the consent form to keep. A copy of the consent form will also be included in your medical notes. If you decide to take part and sign a consent form you are still free to withdraw from the study at any time. If you decide not to take part or would like to withdraw you do not have to give a reason for doing so and this will not affect your treatment and care in anyway.

If you would like to find out more information about the study, then please do get in touch with Professor Richard Cheston (0117 3288927), the chief investigator, Emily Dodd (0117 3287496) the trial manager or your local researcher XXXX.

What do I do now?

The local researcher will get in touch with you to arrange a time for you to take part in the research. They will be able to answer any questions you may have about the study. If you are happy to take part, they will ask you to complete a consent form.

Contact information

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Thank you very much for your time.