NELFT NHS
NHS Foundation Trust

CARER INTERVIEW INFORMATION SHEET : CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-LDD). A mixed methods feasibility study.

Introduction

Your relative/friend has been invited to take part in Group Cognitive Stimulation Therapy (CST) this research study. CST is a treatment for dementia that involves the individual with dementia taking part in a group that meets twice a week for 45 minutes and they take part in activities such as a life story, discussion of current affairs, puzzles and being creative, which is designed to be mentally stimulating. There is evidence that group CST is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population but it is not used in people with dementia who have learning disabilities.

We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. We would like to find out if the manual and activities that we have proposed are enjoyable and are easy to follow.

We would like your opinion on how your friend or relative experienced the groups they attended as part of this study. Your friend or relative has given us permission to approach you for this.

What will happen if I agree to the interview?

If you agree you will be invited to take part in an interview about the groups your friend or relative attended. The interview will take about 30-60 minutes and can take place face to face or on the telephone. We will audio-tape and transcribe the interview. We will remove any information that could identify you from the transcripts and the recording will be deleted from the digital recorder. The information you give us will help us to check whether the groups were adequately adapted for your friend or relative and if it was enjoyed and affected them in their day to day life. It will also help us to know if running a large study evaluating the effects of CST is feasible.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for you in taking part. However, by taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.

Will my taking part in this study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Personal information will not be included on any of the study questionnaires, and instead, you will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be kept in a locked cabinet, within a locked room. The list that links the ID numbers to your identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any quotations used from the interview will be anonymised in the final report or any publications.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed and we will try to manage these situations as sensitively as possible.

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have an ID number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Prof Aimee Spector who is the Chief Investigator of the research project. The study is being sponsored by North East London NHS Foundation Trust and it is funded by the National Institute of Health Research. They will have no involvement in the conduct of the study.

Who has reviewed the study?

The study has been reviewed by XXX and has also been given a favourable ethical opinion for conduct in the NHS by (insert name)…..Research Ethics Committee

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to the research assistant who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response then you can contact the Chief Investigator (see details below) who will do her best to address the issues. You can also contact the Patient Advice and Liaison Service (PALS) for independent advice (see below). They can give you information about how you can complain formally through the NHS Complaints Procedure. You can also obtain details from your local NHS Trust.

In the event that something goes wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.

PALS address: Whipps Cross University Hospital (main building),
Whipps cross Road, E11 1NR
PALS Telephone number: 0203 594 2040
Email: pals@bartshealth.nhs.uk

Contact for Chief Investigator:

Prof Aimee Spector
Add address
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