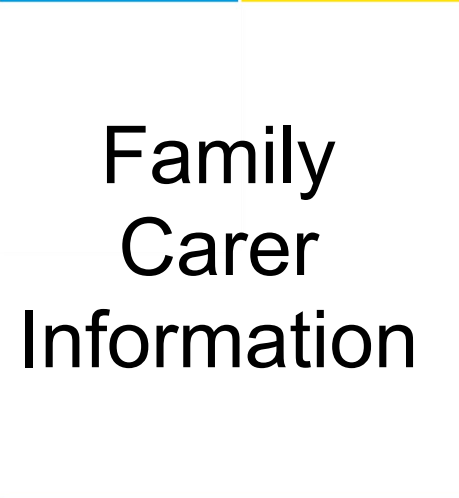




SHIELD
Support at Home:
Interventions to Enhance
Life in Dementia



Carer
Supporter
Programme



SHIELD Carer Supporter Programme

Information for family carers about the SHIELD Carer Support Programme

Thank you for requesting more information about this SHIELD research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. It is also important to discuss this information with the person you care for as they will also take part in this research with you. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are aiming to find out more about the experiences of family carers who support people with dementia at home. In particular we are looking at whether having contact with a Carer Supporter makes a difference to the well-being of carers and people with dementia. We are also interested in the costs of caring, including financial costs. The information that we get from this study will tell us whether Carer Supporter interventions are a valuable part of carer support.

Carer Supporters will provide a listening ear, moral support, encourage involvement and engagement with resources for newer family carers. Carer supporters will also encourage newer carers to look after their own needs, as health often declines in carers if they feel stressed. We hope that the Carer Supporters will help newer carers, or carers moving into a new phase of their care giving, to feel more confident in their role.

Who can take part?

We (the research team) are looking for adult carers (over 18) who care for a family member with dementia who lives at home. Both of you must be living within North East London.

I've expressed interest so do I have to take part?

No, taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. You can ask for more information without

Thank you for your time in reading this.

Do keep this information sheet in a safe place in case you need it in the future.



ISRCTN37956201

Family Carer Information V 4.2 13.08.09.

To talk to a member of the research team please contact:

Dr Karen Burnell
Research Associate
NELFT R&D
1st Floor Maggie Lilley Suite
Goodmayes Hospital
Barley Lane
Goodmayes
IG3 8XJ
Tel: 0844 600 1200 ext 4491
Email: Karen.Burnell@nelft.nhs.uk

The decision about whether or not to take part in this research is entirely yours to make and you will still have the right to withdraw from the research at any time.

Independent Advice

If, after reading this booklet about the SHIELD research, you have further questions and want to talk to someone who is not connected to the SHIELD research team, please contact David Prothero.

David is acting as an Independent Advisor for potential and actual research participants. He is not a member of the research team, but knows about the project due to his role as an Independent Advisor for the SHIELD steering committee. He is available to answer any questions you might have about your rights as a research participant or about the SHIELD research. David will also be able to help you weigh up whether or not to take part.

Phone: 01634 862858

Email: dprothero@easynet.co.uk

Post: David Prothero
C/O for dementia
6 Camden High Street
London
NW1 0JH

committing yourself. Even if you decide to take part, you are free to withdraw from the study at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive from health, social, or voluntary services. Once you have informed us of your decision to withdraw from the research study, any services provided (i.e. having contact with a Carer Supporter) as part of the research study will be brought to an end as they are only available to people taking part in the research.

What will happen to me if I take part?

If you and the researcher agree that the study sounds right for you, then you and the researcher can discuss a time and day to meet up for a face-to-face interview. Alternatively, you may wish to take more time to decide. If and when an interview date and time is discussed, you will be sent a letter confirming details of the date, time and location of the interview, and details of how to cancel the interview if you change your mind.

If you and the researcher meet up for a face-to-face interview, you will be asked to sign a form to say that you have read this information booklet, that you have had the opportunity to ask questions, and that you consent to take part in the research interviews. This form is known as the "Consent form". You will be given a copy of this form for your own records. Your GP will also be sent a copy with your permission to inform them of your participation. This process will be the same for the person you care for as they will also take part in research interviews.

What do the research interviews involve?

All interviews are carried out by research interviewers who have knowledge about dementia and experience of interviewing carers and people with dementia. The first interview is known as the 'baseline' interview. This is quite a long interview, and it may take most of a morning or afternoon to interview you and the person you care for both separately. The next 2 interviews will be shorter, and will take place approximately 5 months, and 12 months after the baseline interview.

We know that caring for a person with dementia puts constraints on your life, and that it is not possible to know what your situation will be in a year's time. Therefore, we are aiming to be as flexible as we can with times, days and venues, so that we can fit in with you rather than for you to fit in with us. For example:

- You can choose the venue for the interview. This may be in your own home, or elsewhere such as a day centre, day hospital or GP surgery, if you prefer.
- You can choose the day of the week, and let us know if an interview must start after a certain time, or finish before a certain time.
- The researcher will contact you a few weeks before your next interview is due, so that you do not need to keep track of appointments many months ahead.

In the interviews, you will be asked about your care giving responsibilities, health, well-being, quality of life, ways of coping, the quality of your relationship with the person you care for, and the support you may receive from other people. The person you care for will be asked questions about their general well-being, quality of life, their relationship with you, and cognitive improvement. We want to get an idea of the financial consequences of caring so you will also be asked about costs to you (e.g. missing work, if you are still working) and about visits made to you and your relative by doctors, nurses or other health care workers. You do not need to be using any of these services at the moment to take part.

What are the possible disadvantages and risks of taking part in the research interviews?

Some people may find it inconvenient to spend time taking part in research interviews. Also, some people may find some parts of the research interview trigger off upsetting feelings, for example feeling sad when talking about the changes they have seen in themselves or the person they care for. The researcher is trained to know how to help you and the person you care for if either of you are upset during the Interview.

What are the possible benefits of taking part in the research interviews?

Most people who have taken part in the research interviews used in this study say that they have found it helpful to talk about their caring experience or the experience of being cared for, and to review what has happened over time. A few people may tell the researcher they are in need of immediate help. The researcher is trained to know what to do in these circumstances, and can assist

are taking part in the research interviews. You can tell others, if you wish to.

If you are randomised to the SHIELD Carer Supporter Programme, your contact details will be sent to the local Carer Supporter Coordinator. The project has a confidentiality policy and also complies with requirements of the Data Protection Act.

The researchers and Carer Supporters have to consider safety as well as confidentiality. If the researchers or Carer Supporters have any serious concerns for your safety, or the safety of the person you care for, or their own safety they will act in accordance with the Borough Council policies in your area, which involves letting their managers know of their concerns, and in some cases sharing concerns with others such as Health or Social Service staff.

What will happen to the results of the research study?

The information from interviews will be analysed at the end of the study (2012). The findings will be published in a report and in scientific journals. A separate report will be written for all those involved in the study, giving information about changes over time and comparing the different experiences of those who were offered a Carer Supporter and those who were not. You and the person you

care for will not be identifiable in any reports as all the collected information will be pooled.

Although neither you nor the person you care for will be identifiable in any reports/publications, you will be able to tell which part(s) of the report concern you, as you will know what kinds of help and support you have received.

Who is organising and funding the research interviews?

This research is being organised by researchers at the North East London Foundation Trust (NELFT) and University College London (UCL). The Programme is funded by the National Institute for Health Research (NIHR) as is part of a 5 year programme of research entitled 'Support at Home: Interventions to Enhance Life in Dementia (SHIELD)'.

Who has reviewed the study?

The research study has been reviewed and approved by the Outer North East London Research Ethical Committee.

What if you want to comment or complain?

If you are unhappy with the conduct of the researcher, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please put your concerns in writing to:

Sandeep Sandhu
NELFT R&D
1st Floor Maggie Lilley Suite
Goodmayes Hospital
Barley Lane
Goodmayes
IG3 8XJ
Phone: 0844 600 1200 ext 4453
Sandeep.sandhu@nelft.nhs.uk

Sandeep Sandhu will aim to deal with your complaint to your satisfaction, but if this is not possible, she will advise you of who to contact to take further action. There are no special compensation arrangements for participants of this trial, but depending upon the nature of your complaint, you may wish to pursue it through University, Social Service or Voluntary Organisations procedures, or through the police. All project workers are covered by appropriate insurance from the organisation with which they are associated.

Or wish to withdraw from the study?

You are free to withdraw from the study at any time and without giving a reason. Once you have informed us of your decision, any services provided as part of the research study will be brought to an end as they are only available to people taking part in the research. The standard of care you receive from health, social, or voluntary services will not be affected.

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential, and in accordance with requirements of the Data Protection Act. You and the person you care for will not be identifiable in any reports/publications as information from all participants will be pooled.

If you both chose to take part, your GP and the GP of the person you care for will be sent a copy of your Consent form. We will not tell anyone else that you

you in planning what to do. The researcher may want to contact others on your behalf. They will not do so without discussing this with you first.



Will I be offered contact with a Carer Supporter?

If you do choose to take part in the research you will have a 1 in 2 chance of being offered contact with a Carer Supporter who will provide a listening ear and 'moral support'. They can also support you to access resources for carers. In some cases carers will be offered a place in a reminiscence group that both you and the person you care for take part in together. Reminiscence work will involve sharing memories in the company of other carers and the people they care for. An experienced facilitator looks after the group and the idea is that people talk and share memories. Most people find these groups enjoyable, but it is important to note that distressing events may be remembered. In these cases the experienced facilitator will be able to support you both if this were to happen.

The decision over whether or not you are offered a Carer Supporter, and whether or not you are offered a place in a reminiscence group will be made through something called the 'randomisation process' (see below). If you are not offered contact with a Carer Supporter, you will be assigned to a 'Treatment as Usual' control condition. Some carers initially offered 'treatment as usual' will go on to be offered a place in a reminiscence group.

If you are offered contact with a Carer Supporter, you will receive written information from the SHIELD Team including details of the local Carer Support Coordinator. The Carer Support Coordinator is the person who organises the

team of Carer Supporters in your area. This is the person who would select a Carer Supporter to suit you, should you choose to have one. It will be your decision whether or not you would like to meet a Carer Supporter.

If you are randomised to receive contact with a Carer Supporter and/or take part in reminiscence group work, you will be asked to complete a feedback form at the end of the study. This form will ask you all about your experiences of meeting with your Carer Supporter and/or taking part in reminiscence group work. By sharing your thoughts and opinions with us, you will help us to understand your experiences of having contact with a Carer Supporter and or taking part in reminiscence group work. It will allow you to tell us things you think are important but that might not have come up during the research interviews. If you choose to fill in this form, all the information you give us will be anonymised and kept confidential.



What is the 'randomisation process'?

Everyone who returns their initial response form will be assigned a code number. If you and the researcher arrange a face-to-face interview, your code number will be put forward to another member of the research team who is in charge of the 'randomisation process'. In this study, randomisation is like tossing a coin where a person has a 1 in 2 chance of 'heads' coming up. We are using randomisation in two stages. In the first stage, if 'heads' comes up for your code number, you will receive written information about SHIELD and the Carer Supporter Coordinator will contact you to answer any questions you

may have. If 'tails' comes up for your code number, you will be sent a letter so that you know not to expect information about Carer Supporters. In the second stage of randomisation the 'coin toss' will decide whether or not you and the person you care for will be offered a place in a reminiscence group. The researcher who interviews you has no control over the randomisation process, and they are not involved in it. The researcher conducting the interviews will not know whether or not you have been offered contact with a Carer Supporter and/or reminiscence work. It is very important that you do not tell the researcher what you are or are not taking part in.

Expenses

Any travel expenses you incur can be reimbursed.

What happens if I stop caring?

We would like to stay in touch with you even if you stop caring. From previous research we would predict that 1 in 4 carers will still be looking after the person with dementia at home after 3 years. Some people with dementia will move into residential or nursing care and others will pass away. It would help us to know what happens to you over the course of the project however much your situation changes. We have planned different interview formats so that we can choose the interview that is most relevant to your circumstances.

