

# Developing a new approach to help people with memory problems after a fall

# Carer information sheet (interview and observation)

You are being invited to take part in a research study. This leaflet explains why the research is being done and what taking part would involve. If you are interested in taking part, please read this information booklet carefully. You can discuss it with others to help you decide.

Thank you for reading this. If you have any questions then please call one of the researchers:

## What is the study about?

People with memory problems are prone to falls and often hurt themselves as a result of falling. Little is known about the best way to support people with memory problems with fall-related injuries or about the help they currently receive. The aim of this project is to develop and test a new approach to help people with memory problems recover after a fall.

## How can I help?

You and your relative/friend have been asked to keep a diary for us about any help you have been given after your fall. This will help us to understand the range of services currently used by people with memory problems after a fall. We would also like to talk to you about any help provided to find out what has been useful and how services could be improved. We will use your experiences and those of other people like you to help us to develop a new approach.

## What is involved?

If you decide to take part in this additional part of the study:

- A member of the research team will contact you to arrange a convenient time to visit you (and your relative/friend) at home
- They will discuss this part of the study in more detail with you, answer any
  questions, and take your consent if you are happy to proceed
- Ask your opinion of any help you have received
- Discuss what extra help might have been useful
- Explore your ideas for improving services

The interview would be conducted by either Miriam Boyles or Alison Wheatley and would last no more than one hour. If at any time you would like to stop, take a break or finish the interview at a different time just let the researcher know.

At the end of the interview you may be asked whether you would be willing to talk to us again. You are under no obligation to agree to a second interview; even you agree that we can contact you again, you are free to decline if we get in touch.

We may also ask whether we can observe one or two services your relative/friend is receiving as a result of his/her fall. If your relative/friend is not able to decide for themselves about the observation, we will provide you with more information and ask you to decide about this additional part of the study.

## What difference will it make?

It is unlikely that taking part will help you directly. However, you may enjoy talking to the researcher. Your ideas and experiences will help us create a new approach to helping people with memory problems who fall in the future.

## Do I have to take part?

No. It is up to you to decide whether or not to take part. If you want to find out more about taking part in research, you can contact the NHS Patient Advisory Liaison Service (PALS) <insert local number>. You do not have to give a reason if you do not want to be involved. Whatever you decide will have no effect on the care you receive now or in the future. If you change your mind, you can leave the study at any time without giving a reason.

# How will my information be kept confidential?

Any information you give us will be kept confidential. Your personal details will only be used if we need to contact you about this research project.

We would like to tape record the interview. We will store the recordings securely. The recording of the interview will be sent to a company outside of Newcastle University to be typed up. The company will not know your name or any other details about you. When we write up the conversations we will change your names and personal details so that you cannot be recognised. We may use your words when we write up our findings but your personal details will not be included.

If you tell us anything that could put yourself or other people at risk, we would have to act on this information by telling your doctor or others involved in your care.

## Who is organising and funding the study?

The study will be organised by a team at Newcastle University. It is sponsored within the NHS by the Newcastle upon Tyne Hospitals NHS Foundation Trust. The study is funded by the NHS through the National Institute for Health Research (NIHR) Health Technology Appraisal programme.

## Who has reviewed this study?

The study has been approved by the National Research Ethics Service Committee Newcastle and North Tyneside 2. The study has also been approved by the Research and Development Departments of the Newcastle upon Tyne Hospitals NHS Foundation Trust and *insert site name*. These research and development departments are responsible for making sure that the research is conducted properly. They may look at data collected during the study to make sure that procedures are being followed correctly.

# What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers first who will do their best to answer your questions (their contact number is 0191 208 1314). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS <a href="http://www.pals.nhs.uk">http://www.pals.nhs.uk</a>) at your local hospital. Their contact number is <a href="mailto:insert local number">insert local number</a>.

# What will happen next?

We will telephone you in the next few days to check whether you are willing to take part in an interview. If you are interested in being involved, we will arrange to

visit you at home. You will have the opportunity to ask any questions about the study before you make a decision.

If you do not wish to take part, you can either let the researcher know when she telephones or contact the project secretary (Beth Edgar, details below) and she will let the researcher know that you do not wish to take part or to be contacted.

## Contact details

If, at any time, you need to get in touch with the research team you can contact them via Beth Edgar, the project secretary:

Beth Edgar (0191) 208 1314

Email: <u>beth.edgar@ncl.ac.uk</u>

Post: Biomedical Research Building,

Campus for Ageing and Vitality,

Newcastle University,

Newcastle upon Tyne, NE4 5PL