

## **Caring about Carers: Information Sheet**

### *About the study*

Caring about Carers project, is a sub-project of Meaningful Mobility, a European Research Council funded study is carried out at the Faculty of Spatial Sciences, University of Groningen and has been approved by the Faculty of Spatial Sciences' Research Ethics Committee. The research team consists of social scientists who specialise in later life mobility, but who do not have medical knowledge about memory or physiological issues.

### *Purpose*

Many older adults with memory issues are cared for by someone who is themselves an older adult. Therefore, the carers own mobility is influenced by their role and the responsibilities it brings. Their mobility is further influenced by the support they receive, which can be formal or informal. The function of such support is also varied, ranging from emotional support and companionship to tangible and informational support. Thus, the aim of this study is to understand the mobility of carers and how supports play a role in that mobility.

The findings from this research will inform policy and other support initiatives for older people, especially those who care for individuals with memory issues or stroke survivors. The research team will inform the participants about the most important findings of the study. This typically happens one year after your participation.

### *Participation*

Participation will not involve any costs for you. You are eligible to participate if you indicate that you:

- Are aged 55 years or older
- Are the primary carer for an individual who is also 55 years or older and has memory problems.
- Live in England, UK
- Are willing to draw three pictures concerning your life as a carer and send them to the research team.

Participation in this study is voluntary. As a participant, you can always change your mind and stop participating at any time by notifying the research team. If you decide to stop participating in the study, you do not need to provide a reason for your decision, and you can request that your data is destroyed. Your participation in the study ends when:

- After the interview has been completed.
- You decide to stop participating.
- The researcher, in consultation with you, sees that it would be in your interest to stop.
- The funder or the Spatial Sciences Faculty Board decide to stop supporting the study.

### *Data collection*

For this study, you will be asked to participate by creating three drawings and taking part in one interview. The research team will provide all the necessary information remotely, via email or telephone.

During our first meeting, the research team will go through the information sheet with you and discuss the consent process. This may also be done via email unless you prefer. You will then be given time to go through the process and digitally give your consent. If this is not possible, verbal consent can also be given on a recording device. During this first meeting, we will ask for your phone number for the telephone interview.

Afterwards the researchers will ask you to:

- Draw three pictures, one concerning your life before becoming a carer, a second concerning your present life and a third concerning your future expectations. These will need to be photographed or scanned and sent via Unishare to the researchers (see Unishare information sheet for instructions on this). The researchers will also explain this.

After the study period is complete, the research team will contact you to arrange a time to conduct the interview. This interview will last approximately one-hour and will consider your mobility as a carer, the social support you may or may not receive and your drawings. This interview will be audio recorded and take place either on the telephone or via a video conference platform. The choice of which will be yours to make.

The research team will carefully orientate you to each of the research activities. The research team are interested in your stories and your experiences of being a carer. There are no right or wrong answers and any information you provide is valuable to us.

Should new information about the study arise that is relevant to you as a participant, the researcher will inform you. At this point you will be asked whether you want to continue your participation or not.

#### *Risks of participation*

The researcher may focus on sensitive topics for you and this may evoke strong emotions during the interview. Should this happen, the research team will do their best to acknowledge your response and take a break from the interview if necessary. Please note that you do not need to answer any questions you do not want to answer.

There may be situations where the research team has concerns for your overall health and safety. In case of immediate danger or serious harm, the research team will first discuss their concerns with you and subsequently report to the responsible institutions.

#### *What we do with your data*

For this study, we will collect personal data. Collecting, analysing and storing your data is needed to answer the research questions. We collect your contact information, as well as data from the drawings and interview. The data that is presented in reports and publications about the study can never be traced back to you as a person.

To protect your privacy, your data will be securely stored on University of Groningen servers. Only the research team have access to your data and to log on to the servers, they need a password and SMS-token. The servers for data storage are not linked to external networks or host internet services and are thus highly secure. Any data transfers (such as that between PhD students and supervisors) shall take place via secure FTP (file transfer protocol) servers, or at face-to-face meetings. The project complies with the General Data Protection Regulation.

Furthermore, all data will be pseudonymised as soon as possible, which means that personally identifiable information is replaced by one or more artificial identifiers. We call these pseudonyms. This makes it much more difficult to identify you as a person. The research team will be able to link your personal details (contact information) to the other data. We will store your personal details in a file that will be kept separate from the other data that you provide. At a later stage, for instance in reports, your data will be fully anonymised, which means that they cannot be traced back to you as a person. The research team will maintain the rights to data sharing and use (such as for future publications). Your data will be stored for ten years, in accordance with the data regulations of the University of Groningen.

If you would like to have more detailed information about how we protect your data, please contact the research team and we will be happy to answer your questions. Additional information with regard to your data and privacy is available on the project website: [www.rug.nl/meaningfulmobility](http://www.rug.nl/meaningfulmobility).

#### *Your rights*

For general information about your rights with regard to the processing of your data, it is recommended that you first consult the Principal Investigator. You can also contact the Data Protection Office of the University of Groningen (please see the contact information in section 5).

#### *The right of access and correction*

You have the right to have access to your own data, to see what data has been collected, and to request modification of any erroneous data that may have been recorded unintentionally. You can get access to your data by contacting the research team (please see the contact information in section 5).

#### *The right to withdraw your consent*

You have the right to withdraw your consent to participate in the project and to the processing of your data. Withdrawal is possible until the findings have been published. You do not have to provide a reason for your withdrawal but if the request to withdraw comes after data has been pseudonymised and incorporated in the analysis, it may not be possible to withdraw the entire dataset. However, every attempt will be made to extract the data up to the point of publication. If you decide to withdraw your consent you can contact the researchers.

#### *Contact information*

The research team is Dr Tess Osborne (Post-Doc Researcher) & Thomas Lowe MSc. (PhD Researcher). You can contact the research team by phone (07957757805) or by email via [meaningfulmobility@rug.nl](mailto:meaningfulmobility@rug.nl).

Please contact the research team if:

- You have any questions concerning your participation or you want to stop your participation
- You experience any problems, for instance if you cannot send the drawings
- Your contact details change.

The other members of the broader research team are mentioned on the project website: [www.rug.nl/meaningfulmobility](http://www.rug.nl/meaningfulmobility).

#### *The Independent Advisor*

For independent advice about your participation, you can contact the project's independent advisor. She knows a lot about the study, but is not directly involved in it. Contact details: Prof. dr. Hinke Haisma, Adjunct professor in Demography, tel. +31 (0)50 363 86 54, email: [h.h.haisma@rug.nl](mailto:h.h.haisma@rug.nl). Available on Mondays, Tuesdays and Thursdays.

#### Data Protection Officer of the University of Groningen

For general information about your rights with regard to the processing of your data, you can contact the Data Protection Office of the University of Groningen. Contact details: Mr. Arjen Deenen, tel.: +31 (0) 50 363 57 51, email: [a.r.deenen@rug.nl](mailto:a.r.deenen@rug.nl). Available Monday Friday