

## **INFORMATION SHEET FOR PARTICIPANTS**

*REC Reference Number: HR/DP-23/24-40947*



### **Exploring the feasibility of delivering an online Compassion Focused Therapy (CFT) group intervention for carers of people with dementia who have moved to a care home.**

You are invited to participate in this research project which forms part of my Doctorate in Clinical Psychology. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the project?**

Caring for someone with a diagnosis of dementia can be associated with a broad range of emotions and experiences. We know that many families will have to make the decision for the person they are caring for to move into a care home. This decision can be associated with a wide range of emotions.

The purpose of this project is to explore how feasible and acceptable it is to provide an information and support group-based training programme for family carers, when the person with dementia that they support has recently moved into a care home.

The group will be based on Compassion Focused Therapy (CFT), which is an evidence based psychological intervention that aims to support people to become aware of and notice difficult experiences or emotions and respond to them in a different way. It teaches different ways to be compassionate to yourself, to others, and to receive compassion from others.

#### **Why have I been invited to take part?**

We are inviting carers of people with dementia to take part in this study.

You can take part in this study if:

- You are an unpaid adult carer of people with dementia. For the purpose of this study, unpaid carers are defined as someone who has been involved in the care and support of the person with dementia while living in the community and has been involved in the move of the person with dementia to a care home, for example partners, spouses, family and friends.
- You are at least 18 years old.
- You are willing to participate in a group intervention programme.
- You have internet access to enable participation in the group intervention.
- The person with dementia has moved to a care home in the last 12 months.

## **What will happen if I take part?**

If you are interested in taking part in the study, please complete [this short form](#) to register your interest. After this you will be contacted by Laura Chatland, the researcher, for a short telephone call to complete some checks (e.g., are you aged 18 years or above) and to confirm this is the right study for you. You will be able to ask any questions you have about the group and discuss your involvement.

If this isn't the right study for you, the researcher will let you know and share the details of information and support organisations that might be of interest to you.

If this is the right study for you and you decide to take part, you will be asked to sign a consent form and will be provided with the dates and times of the group sessions. You will be able to contact the researcher (Laura Chatland) via email if you have any questions throughout your participation in the group.

You will be asked to attend five online group sessions on Microsoft Teams. Each session will last 1.5 hours and will take place weekly. The group will be facilitated by a trainee clinical psychologist. The group will have some other carers of people with dementia who have recently moved into a care home.

You will also be asked to complete 7 different questionnaires before the first group session and again after the final group session. You will also be asked to complete the same questionnaires 4 weeks after the end of the group. These questionnaires will ask about your emotions and wellbeing and relationships. These questionnaires will also ask sensitive questions about your mental health including about feelings, mood, and questions about self-harm. Should you disclose any information that leaves the researcher with concerns about the immediate safety for yourself and/or others, this will be followed up by a phone call from the researcher to ensure you are able access the right support.

We will also ask you questions about how you describe yourself for example, age, ethnicity, gender, relationship status, living arrangements, and employment status. We will also ask about the person you are caring for, for example, your relationship to the person with dementia, and the length of the caregiving relationship. We are asking these questions to find out who has accessed the group and to think about how we can make the group accessible for a broad group of carers.

At the end of each group session, you will also be asked to complete a brief session feedback form. This will take approximately 5 minutes.

It is estimated that it will take 60 minutes for you to complete these questionnaires.

You will also be invited to take part in an interview about your experience of the training. The interview be after the final group session and will last up to 1 hour and will take place online. The interview will ask you questions such as "How satisfied are you with the group?", "How would you best describe your experience of the group?" and "How has your participation in the group changed your daily life?".

The interview will be audio-recorded with your consent to allow for later transcribing and analysis.

If you are happy to take part and the research team have answered any questions you have, you will be given this information sheet to keep and asked to sign a consent form.

### **Do I have to take part?**

No. Your participation is completely voluntary.

You should only take part if you want to and choosing not to take part will not disadvantage you in any way.

If you do decide to take part, you can leave the research at any time without a reason being provided.

### **Incentives**

To compensate you for your time, you will receive a £40 voucher. This will be as follows:

- £10 voucher for completing the questionnaires ahead of the first group session.
- £10 voucher completing the questionnaires following the final group session, including a feedback questionnaire.
- £10 voucher for completing the questionnaires as a follow up 4 weeks after the group has ended.
- £10 voucher for completing the post-group interview.

You will receive the total sum after the research is completed.

If you withdraw from the group intervention at any time, you will receive a voucher for the amount equal to the parts you have completed.

### **What are the possible risks of taking part?**

If you decide to take part, you will be receiving an intervention in a group setting which may involve the discussion of sensitive topics that may be associated with some emotional distress.

The group facilitators will promote an empathetic, safe, and compassionate group environment. This will include setting group guidelines in collaboration with the attendees at the first session. You will be able to take breaks whenever needed and the researcher will provide information about additional support services with everyone who expresses an interest in the group.

It is possible that in group discussions and/or conversations with the researcher, you might disclose an urgent mental health risk, or potential risk of harm to yourself or others. If this were to happen, our priority would be to keep you (or others) safe. We will always aim to work closely with you, where possible, to ensure that you are directed to and able to access the right care and support for your needs. This can include informing the relevant service/professional who might be in the best position to provide that support and care.

Where possible, this will be a transparent process undertaken with your knowledge. If you would like to talk about this, please speak to the researcher on the contact details below.

### **What are the possible benefits of taking part?**

The study will provide participants with an opportunity to learn and try new strategies to manage emotions which they will be able to continue to use after the group intervention ends. You may also benefit from meeting other people with similar experiences in the group. You may find it interesting to contribute to research.

### **Data handling and confidentiality**

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018).

All personal information will be kept confidential and will be accessible and used only by the clinicians and researcher working on this project.

The research team will be responsible for assigning each participant an anonymity code.

Your name and personal identifiable information will be stored securely and separate from other information provided, for example, questionnaires and interview recordings, in electronic password-protected files. All data provided will be stored in a secure online storage repository.

The main researcher Laura Chatland will be responsible for the transcription of the interviews.

Contact details of participants will be stored in a separate, password protected spreadsheet stored on a secure drive that will not be linked to the original research data and will be retained until the research has been written up and published to share the study findings. Contact details of participants will be deleted no later than 31<sup>st</sup> May 2025.

You will not be identifiable in the final research paper. We may include quotes from your interview to highlight the experience of the group in the final research paper, however no personal identifiable information would be reported alongside this.

The expected date that your personal data will no longer be stored in an identifiable format for the purposes of this project is 31<sup>st</sup> December 2024 when the data collection and group has been completed.

An anonymised copy of the data gathered from the study will be retained for 10 years, in line with the King's College London Data Retention policy. This will include your participants number, quotes from your interview and your scores on questionnaires. You will not be able to be identified from the information stored.

It is important that you are aware that there is a limit to the level of confidentiality provided. There may be instances where the researcher might have to break confidentiality. We would only ever break confidentiality in the case that you reveal something which caused us to be concerned for your immediate safety or the safety of others, in which case we

may need to contact appropriate services. We would always aim to inform you first and involve you in this process.

King's College London has a responsibility to keep information collected about you safe and secure, and to ensure the integrity of research data. Specialist teams within King's College London continually assess and ensure that data is held in the most appropriate and secure way.

### **Data Protection Statement**

If you would like more information about how your data will be processed under the terms of UK data protection laws, please visit the KCL website here:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

If you are unable to access the internet to view this statement, please request a copy from the researcher.

### **What if I change my mind about taking part?**

You are free to withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way or affect any care or services you receive. Withdrawing from the project will not affect the current or future involvement you may have with the research team, health professionals or any care that your relative might currently receive or access in the future.

You can withdraw your data from the project up until 31<sup>st</sup> October 2024 after which withdrawal of your data will no longer be possible as the data will have been anonymised and analysed for the final write up and report. If you choose to withdraw from the project, we will not retain any of the information you have provided to us thus far.

The feedback questionnaires completed after each group session will be anonymous and therefore, cannot be withdrawn if you leave the project.

### **What will happen to the results of the project?**

The results of the project will be written up in a research paper which will be part of the researcher's submission to the Doctorate in Clinical Psychology at King's College London. We also hope to publish and share the research findings in an academic journal and conferences.

A copy of the study results will be shared with participants. You can indicate on the consent form if you would like to receive a copy.

### **Who should I contact for further information?**

If you have any questions or require more information about this project, please contact the researcher using the following contact details:

Laura Chatland, Trainee Clinical Psychologist, Addiction Sciences Building, Institute of Psychiatry, Psychology & Neuroscience, 4 Windsor Walk, London, SE5 8AZ.  
Email: [Laura.Chatland@kcl.ac.uk](mailto:Laura.Chatland@kcl.ac.uk) Tel: 07596 892262

**What if I have further questions, or if something goes wrong?**

If this project has harmed you in any way, or if you wish to make a complaint about the conduct of the project, you can contact King's College London using the details below for further advice and information:

Dr Juliana Onwumere, Department of Psychology, Henry Wellcome Building, Institute of Psychiatry, Psychology & Neuroscience, 16 De Crespigny Park, London, SE5 8AF.  
Email: [Juliana.1.Onwumere@kcl.ac.uk](mailto:Juliana.1.Onwumere@kcl.ac.uk) Tel: 020 7848 0197

Thank you for reading this information sheet and for considering taking part in this research.

## **Support services**

Below are support services that you might find helpful:

### **1. NHS emergency services**

NHS emergency services

Tel: 999

South London and Maudsley NHS urgent mental health crisis line (for those living in South East London)

Website: <https://slam.nhs.uk/crisis>

Tel: 0800 731 2864 (choose option 1)

Local NHS mental health crisis lines

You can find out how to contact your local NHS crisis line here:

<https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

### **2. NHS non-emergency services:**

Website: <https://111.nhs.uk/>

Tel: 111

South London and Maudsley NHS Talking Therapies

Website: <https://slam.nhs.uk/talking-therapy>

Tel: 020 3228 6000

### **3. Local dementia support organisations**

Alzheimer's Society Lewisham

Website: <https://www.alzheimers.org.uk/support-services/Lewisham%20Local%20Services/Lewisham%20Dementia%20Support/regional>

Tel: 020 7423 5107

Alzheimer's Society Croydon

Website: <https://www.alzheimers.org.uk/support-services/Croydon%20Local%20Service%20Office/Dementia%20Adviser%20Croydon/regional>

Tel: 020 8653 2818

Alzheimer's Society Southwark & Lambeth

Website: <https://www.alzheimers.org.uk/support-services/Southwark%2BLocal%2BServices/Dementia%2BAdviser%2BSouthwark/regional>

Tel: 020 7735 5850

#### **4. Local carers organisations**

Southwark Carers

Website: [southwarkcarers.org.uk](http://southwarkcarers.org.uk)

Tel: 020 7708 4497

Carers Hub Lambeth

Website: <https://www.carershub.org.uk/>

Tel: 020 7501 8972

Carers Lewisham

Website: <https://www.carerslewisham.org.uk/>

Tel: 020 8699 8686

Carers Support Centre Croydon

Website: <https://www.carersinfo.org.uk/>

Tel: 020 8649 9339

#### **5. National carers support organisations**

Carers UK

Website: <https://www.carersuk.org/>

Tel: 0800 808 7777

Carers Trust

Website: <https://carers.org/help-for-carers/introduction>

Tel:

#### **6. Dementia national support organisations**

Alzheimer's Society

Website: <https://www.alzheimers.org.uk/>

Tel: 0333 150 3456 (Support Line)

Admiral Nurses dementia helpline

Website: <https://www.dementiauk.org/information-and-support/how-we-can-support-you/what-is-an-admiral-nurse/>

Tel: 0808 808 7777

Dementia UK

Website: <https://www.dementiauk.org/>

Tel: 0800 888 6678



## 7. Other useful national support organisation

### Samaritans

Web: <https://www.samaritans.org/>

Tel: 116 123

### MIND

Website: [www.mind.org.uk](http://www.mind.org.uk)

Tel: 0300 123 3393

### South East London Mind

Lewisham Tel: 020 3228 0760

Lambeth & Southwark Tel: 020 8159 8355

### Mental Health Foundation

Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

Tel: 020 7803 1100