

Participant Information Sheet (PIS)

Title of Project: The experience of family carers and keeping in regular contact with loved ones who permanently live in a care home during the COVID19 Pandemic: A UK perspective

Name of Investigators: Dr Kathryn Hinsliff-Smith & Prof Jayne Brown

You have been invited to take part in a research study. Before you decide whether 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 friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part or not.

What is the study about?

In the UK on the 23rd March, 2020 the UK population was informed to “stay at home, protect the NHS, save lives” (Gov. UK 2020a). This included any visits by family to loved ones living in a care home including residential care home settings. However, limiting personal contacts and interactions with care home residents and their family can cause undue distress to residents. How does the restriction on visits affect family members, and how are they adjusting?

The aim of this COVID-19 related study is to explore the experiences for family who are unable to visit their relatives (parent, brother, sister, Aunt or Uncle) who permanently reside in a care home. This relates to ‘usual’ family visits as well as compassion visits that may be made at a time when end of life (EOL) procedures would be followed. We want to understand current interactions by family and their relatives living within a care home during the period of a UK wide lock-down and continuing post care home visits are allowed by family.

It is proposed through the findings from this COVID-19 care home study to co-develop resources that facilitate good practice with practical messages of how family can be actively engaged in the continuing care of a loved one in a care home when restrictions may be in place. For example this can occur when there is an outbreak of a more common infection but where the care home is restricting visitors.

Why have I been chosen?

You have been invited to take part in the study as you have self-identified as a carer for a family relative who permanently lives in a care home and where you usually (pre COVID restrictions) visited them at least once per week or at least 3 times per month.

What does taking part involve?

The study will involve you agreeing to be interviewed online using a recordable source (similar to FaceTime or WhatsApp) but one which is encrypted for research purposes and the interview can be recorded. You will need to have access to either a smart phone, iPad or a PC that has reliable internet connection. Interview times and dates will be agreed between the researcher and yourself and will be no more than on 4 agreed weekly occasions during the enforced lock down and 1 occasion once restrictions are lifted and visits to care homes are permitted to a maximum of 5 interviews in total. If you become tired or upset during the interview will cease and another time and date can be made to resume the interview if you chose.

Do I have to take part?

Taking part is entirely voluntary. It is up to you to decide whether or not to take part. You will be asked to verbally agree to consent for which our researcher will read out our ethics approved **Consent Form** at the commencement of the 1st interview taking place and a copy will be posted you.

I am interested in taking part, what do I do next?

If you are interested in participating please contact the research team using the contact details listed at the end of this letter. A member of the study research team will then make contact with you directly and will introduce themselves as from DMU and the name of the study.

What if I agree to take part and then change my mind?

If you decide to take part you are still free to withdraw at any time without giving a reason and without it affecting your participation in the study at all. Any data collected up to the point of withdrawal may still be used.

What are the possible disadvantages and risks of taking part?

There is good evidence that the experience of being interviewed may be therapeutic. However, there is potential for you to become emotionally distressed during the interview if discussing sensitive or distressing life events. The researchers who will be interviewing you are highly experienced in undertaking sensitive research data collection with a wide range of participants.

What are the possible benefits of taking part?

Although there will be no direct benefit to yourself the study will provide information which will help to improve quality of services offered during a period of enforced restrictions of visits to care homes.

What if something goes wrong?

In the unlikely event of you becoming distressed during the research and you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal University complaints mechanisms should be available to you. If you have a complaint regarding anything to do with this study, you can initially approach the lead investigator Dr Kathryn Hinsliff-Smith (see end of this for contact details). If this achieves no satisfactory outcome, you should then contact the Administrator for the Faculty Research Ethics Committee, Research & Commercial Office, Faculty of Health & Life Sciences, 1.25 Edith Murphy House, De Montfort University, The Gateway, Leicester, LE1 9BH or hlsfro@dmu.ac.uk

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept on a password protected database and encrypted recording portal and is strictly confidential. You will be given either an identification code or pseudonym which will be used instead of your name. Any identifiable information you may give will be removed and anonymised. We may use quotes from your interview in reports and other documents however, although you may recognize something you have said, these will not be attributed to you.

Data collected will be retained for 5 years after the study has been completed according to DMU policy. Members of the Faculty of Human Research Ethics Committee may require access to check that the study has been conducted in accordance with the approval.

What will happen to the results of the study?

The findings from this study will be used in various scholarly outputs including academic journal publications and conferences. It is our intention that the findings from this study will be disseminated to care homes directly, with care home and carer forums and shared with the CQC for care home inspections as potential good practice. This is an item included in the consent form.

Who is organising and funding the research?

This study is funded by and organised by academics at De Montfort University Faculty of Health and Life Sciences, Leicester.

Who has reviewed the study?

This study has been reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee (**Ethics number 3607**).

Contact for Further Information

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Thank you for considering taking part in this study