Participant Information Sheet for Carer Interviews and Arts Based Activities

‘Making the invisible visible’: identifying and responding to unpaid carers who experience domestic abuse from end-of-life care recipients (CEDA Study)

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ERGO number: 107339
IRAS number: 359868
REC reference: 25/YH/0228

- You are being invited to take part in the above research study.
- To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve.
- Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research.
- You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Around 2.4 million people have experienced Domestic Abuse (DA) in England and Wales. DA is defined as “controlling, coercive or threatening behaviour, physical, sexual, economic, psychological and emotional abuse perpetrated by current or former partners, or family members over 16 years of age”. People providing unpaid care to someone with a life-limiting illness are at increased risk of DA when the person they are caring for is, or has been, abusive. Carers are vulnerable to DA because illness can make DA more likely, worsen power imbalances in relationships, and because carers often spend long periods at home with alone the perpetrator.

In this study we will talk to carer-survivors who experienced DA while providing End of Life Care (EOLC). We want to find out about their experiences and support needs. We will also talk to Health and Social Care Professionals (HSCPs) to find out how much they know about carer-survivors, how they can support carer-survivors, and what training they need.

Our Study Team will work with a group of people who have expertise in DA among carers of people at the End of Life (EOL). They will use the study findings to produce guidance for HSCPs and make recommendations to inform policy and practice.

Why have I been asked to participate?

You have been asked to take part in this study because you experienced DA from someone you were caring for who was at the End of Life. We are inviting people to share these experiences with us so that we understand them better. This will help us when we work to produce guidance for HSCPs to help them identify and support carer-survivors. It will also help us to make recommendations to inform policy and practice around carer-survivors.

What will happen to me if I take part?

The researcher will go through the study with you and answer any questions you may have. If you are happy to take part, we will ask you to give your consent. The consent form and a Participant Information Sheet (PIS) will be emailed or posted to you (depending on your preference) before you take part in the study.

Next, the researcher will contact you again, answer any further questions, and discuss how you would like to be involved in the study. This can be by sharing your experiences in an interview with a researcher but could also be by writing about your experiences or using photographs (not of people), or other objects to tell your story.

Before you take part, the researcher will ask you to either complete the consent form in writing or, if you prefer, the researcher will read through the questions on the consent form and ask you for verbal consent for each item, this will be audio recorded. If you complete the consent form in writing, we ask that you return it by email to ceda@soton.ac.uk or in the post in the pre-paid envelope provided.

The researcher will countersign the consent form, which will then be sent back to you for your records. If you share your experiences with the researcher in an interview or a conversation, these activities will be audio-recorded and will last no more than two hours.

Are there any benefits in my taking part?

You may find it helpful to talk about things you haven't been able to share with family or friends. You may also value the fact that your involvement will help us develop resources and recommendations that could support other carers experiencing DA.

You will be paid £25 in shopping vouchers to thank you for your time.

What are the possible disadvantages and risks of taking part?

We do not anticipate any significant risk to those taking part; however we recognise it is possible that sharing personal experiences of DA may be upsetting. If you feel uncomfortable or distressed at any time while sharing your experiences, you can take a break from the activity or leave the activity if you do not feel able to return. If you do take a break or leave,

a member of the CEDA Study Team will contact you later to see if you would like any support.

The following sources of advice or help are free, independent of this study, and may be useful:
National Domestic Abuse 24-hour freephone helpline 0808 2000 247
Women's Aid (www.womensaid.org.uk) Email: helpline@womensaid.org.uk
Victim Support (www.victimsupport.org.uk) Support line 0808 1689 111

Do I have to take part, and can I change my mind?

It is entirely up to you whether or not you take part. If you decide not to take part, you do not have to give a reason. If you decide to take part, you are still free to withdraw without giving a reason. There are two options for withdrawal that are available to you should you wish:

Option 1 – No further contact: we would no longer contact you about the study but would still have your permission to retain and use information provided so far.

Option 2 – No further contact and use of information: we would no longer contact you, and information collected previously would no longer be available to researchers. We would only hold your information for our regulators' use. Such a withdrawal would prevent your information from contributing to further analyses. Please note that you can only choose this option for withdrawal up until the time we begin our analyses; once we start analyses, it is not possible to remove data.

If you would like to withdraw from the study, please contact the Study Team at ceda@soton.ac.uk

What will happen to the results of the study?

The funder of the study, the Marie Curie Research Grant Scheme, will receive a full report on the study, which they may chose to share widely. We hope that the results of the study will be published in journals and presented at conferences. We may also share them on social media and with journalists who are reporting on stories of domestic abuse or unpaid care. If you would like a summary of the results of the study, please contact the CEDA Study Team ceda@soton.ac.uk . You may be invited to attend NIHR ARC [1]events where results are presented, and updates will be available through Marie Curie's newsletters and their website.

Will I be contacted in the future about this study?

As part of the consent form, we will ask you whether you would like to be contacted about taking part in future research associated with this study. We will also ask whether you would

[1] National Institute for Health and Care Research, Applied Research Collaboration

like to receive study updates and results through newsletters that are posted or emailed. All future contact about the study or possible future research is optional. It is entirely up to you whether you would like to receive any further contact once your participation in the study is complete.

Who is organising the study? Who has reviewed it?

The study is organised by the School of Health Sciences, University of Southampton. The funder is the Marie Curie Research Grant Scheme. The study has been reviewed and received a favourable opinion from Leeds East Research Ethics Committee.

What if there is a problem?

- If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.
- If you remain unhappy or have a complaint about any aspect of this study, please contact the Head of Research Ethics and Governance (023 8059 5058, rgoinfo@soton.ac.uk), University of Southampton

Further information and contact details

If you require information about his research project that has not been covered in this information sheet, please contact:

- The research team via email: ceda@soton.ac.uk
  Telephone: 023 8059 7581
- The Chief Investigator, Michelle Myall:
  Building 67 Room 4053,
  School of Health Sciences,
  University of Southampton,
  Highfield,
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  Email: m.myall@soton.ac.uk

Data Protection Privacy Notice

How will we use information about you?

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, and we will need to use information from you for this research project. This information will include your

- initials
- name
- contact details
- email address

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Southampton is the sponsor of this research.

The University of Southampton is responsible for looking after your information. We will not share your information related to this research project with other organisations.

We will keep all information about you safe and secure by:

- Storing your personal details (for example your name) separately to your interview or study activity data
- Storing your personal details in a locked filing cabinet or on a password protected computer
- Restricting access to your personal details to members of the CEDA Study Team only

We have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when we legally have to. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website

Your data will not be shared outside the UK

Ho will we use the information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for the minimum period of time required by the University of Southampton policies. Your study data will then be fully anonymized and securely archived or destroyed.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information from:

- the Health Research Authority (HRA) leaflet available from [www.hra.nhs.uk/patientdataandresearch]
- by sending an email to University's Data Protection Officer (data.protection@soton.ac.uk).
- by asking one of the research team or from our general privacy policy.
- by sending an email to ceda@soton.ac.uk, or by ringing us on 023 8059 7581

Further information

During your interview or conversation with a researcher from the CEDA study team, you will be asked to share your experiences of DA. For example, you may be asked what impact it has had on you and what support you received. You will also be asked some background questions including your age, gender and ethnicity. We ask these background questions to help us understand how different identities shape experience of DA, help seeking and support needs. With your consent, the interview or conversation will be audio-recorded.

Any information that you give us in an interview, conversation, written document or other material will be anonymised and will not be linked to your name. No identifiable images (for example, people) should be included in any photographs or other objects you use to help you talk about your experiences, to prevent identification. You will not be identifiable from any of the reports arising from the study. A summary of results will be sent to any participant who requests it.

Any audio recordings of study activities (for example an interview or a conversation about photographs) will be transcribed (written out word for word) by a university approved transcriber, who has signed a confidentiality agreement. To maintain confidentiality, we will remove any identifiable data from any documents that you give us (for example a written account of your experiences) and any transcriptions of audio recordings. In addition, we ask that any photographs or other objects used to help you talk about your experiences, do not include images of people. We will give you a different (pseudo) name and a study identification numbery (ID). The audio-recordings and written documents will be stored on password-protected University desktop computers and laptops and will only be accessed by the study team and regulatory authorities (for checking the quality of the research). After transcription, and cleaning of transcripts, recordings are deleted.

Things that are said or written by you in study activities may be quoted in reports of study findings and publications, however, names and personal details will be removed to protect identities. Data collected for this study might also be shared in the future with other academic researchers who seek permission from us for studies that are unknown at this time. Any data shared with other researchers, will **not** include your name or other personal identifying information. Audio-recordings will **not** be shared with other researchers, or with anyone outside of the Study Team.

If we have significant concerns about your welfare or the welfare of someone else, we are required to report this and if there is immediate danger, to call 999. This is never a decision we make lightly, and we will always try to discuss it with you first and include you in the process.

Thank you for taking the time to read this information sheet and for considering taking part in the research.