Researcher: Mollie Price

Project title: Exploring the experiences and unmet needs of informal carers of people with both cancer and dementia.

Invitation to participate:
I am inviting people who provide unpaid care to a relative or friend who has both cancer and dementia to take part in an interview study. In order to take part, you must be living in the UK and be able to speak fluent English. Taking part is voluntary; it is up to you to decide whether or not to take part. It is important for you to understand what the research is about and what it will involve. Please take time to read the following information carefully. If anything is unclear to you or you would like more information please ask.

What is the project about?
The purpose of this study is to learn about carers’ experiences of caring for someone with both cancer and dementia, and to highlight any unmet needs they might have and how these might best be met.

What will I be asked to do?
This study involves taking part in an interview. You will be asked to talk about your experiences as a carer, and the challenges/supportive needs you have. Example questions include:
• What aspects of your life have been affected the most by your carer role?

• What does your typical day involve as a carer for someone with cancer and dementia?

You will also be asked to complete a short sociodemographic questionnaire. Example questions include:

• What is your age?
• Are you currently in paid employment?
• What is your relationship to the relative or friend whom you are providing care for?

Total participation will take approximately 60-90 minutes.

**What are the advantages and disadvantages of taking part?**

The information received from carers who participate in the interviews will be used to inform the development of an intervention for carers of people with both cancer and dementia at Carers Leeds, with the aim of meeting carers’ supportive needs and improving carer wellbeing.

Taking part is not expected to cause any discomfort or distress. If you do experience feelings of upset or distress following the interview, you can access emotional or practical support and advice from the following sources:

• **Carers Leeds Advice Line**: 0113 380 4300 (Mon-Fri 9am-4.30pm); http://www.carersleeds.org.uk/our-support-service/

• **Admiral Nursing Direct Dementia Helpline**: 0800 888 6678 (Fri-Tues 9am-5pm; Weds & Thurs 9am-5pm; 6pm-9pm);
How will my information be used?
The interviews will be audio recorded and transcribed verbatim following the interview. Participant names will be changed during transcription as to remain anonymous, and any information discussed in the interviews that make a participant potentially identifiable will not be transcribed (e.g. address). Once transcribed, interview recordings will be deleted. The people with access to the full interview transcripts are the PhD researcher, Mollie Price, and the PhD supervisors: Dr Laura Ashley, Professor Claire Surr, and Professor Brendan Gough. The findings from the interviews will be used to inform the development of an intervention for carers of people with comorbid cancer and dementia at Carers Leeds. Additionally, the study findings may be presented at academic conferences, published in academic journals, and/or publicised online (e.g. via ResearchGate). You will not be identifiable in any reports of the results. The interview transcripts may be kept by Leeds Beckett University for up to ten years and used for additional analyses related to other aspects of caring for someone with cancer and dementia.

Will my information be confidential?
Disclosed information will be stored securely and used solely for research purposes. All the information you provide will be treated confidentially. Exceptions to confidentiality can only be made in the unlikely event that
information is disclosed to suggest that yourself or another person is at risk of harm. In such cases information will be reported following local safeguarding procedures.

Can I change my mind?
Yes, you can stop taking part in the study at any time. You can also ask for your interview to not be used in this study and the recording and/or interview transcript will be deleted. You will not be asked to provide a reason why. If you would like to withdraw your data after taking part, you can do so by contacting Mollie Price (see section below) by: 31st December 2017. When you complete the sociodemographic questionnaire, you will be asked to create a unique code (first three letters of your mother’s maiden name followed by the first three digits of your date of birth) and you will need to quote this code in order to withdraw your data. This is to allow us to identify your questionnaire and interview transcript as participant names will be removed or changed to maintain anonymity.

Who can I contact for further information?

Reseacher: Mollie Price
Email: m.price@leedsbeckett.ac.uk
Phone: 0113 812 8969
If you wish to talk to an independent representative outside of this research study, please contact Dr Andrew Wilson (Chair of the Psychology Local Research Ethics Committee, Leeds Beckett University) on 0113 812 5581 or a.d.wilson@leedsbeckett.ac.uk.

**What happens next?**

Please think carefully about whether or not you wish to take part in the study. If you do wish to take part, you will be asked to complete a consent form before completing the questionnaire and taking part in the interview. Thank you for considering participating.