

The D-DRINC Study : Participant Information

Sheet [Standard Version] IRAS Project ID: 317892

Long Study Title: An Inclusive approach to understanding the barriers and facilitators of drinking, for people living with dementia in a Care Home – **The D-DRINC Study**

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If you are interested in taking part in this study, please fully read the information below.



What is the D-DRINC Study?

The D-DRINC study is part of my PhD project.

The aim of the D-DRINC study is to better understand how residents drink within a care home setting. We would like to understand what may or may not help someone living with dementia to drink.

If we can better understand the kinds of things that help people living with dementia to drink, then we can then work to develop interventions, which might help to improve drinking and so help prevent dehydration for care home residents, especially those living with memory problems.

Who are we looking to recruit to take part in the study?

We would like to speak with anyone who works within the care home. We also would like to speak with people who are responsible for the management and leadership of the care home. We would like to speak to family caregivers and visitors of residents within the care home. We would like to speak with health professionals who visit the care home and provide care or support to residents within the care home. We would also like to speak to care home residents, who have difficulty remembering/ cognitive impairment.

What will study participation involve?

Care home resident

If you are a **care home resident**, and you decide to take part in this study, the researcher (Ellice) will ask you some questions about the study, and if she is happy that you understand the study, then she will ask you to complete a consent form. You can change your mind about taking part in the study and are free to stop taking part in the study at any point.

To take part in the study, we will ask if you are happy to take part in research observations. The research observations will involve Ellice watching the usual daily routines within the care home and taking some notes. Research observations will usually happen within communal areas, such as corridors, the sitting room or dining room. Observations might also happen in bedrooms, because some residents spend more time in their bedroom. Bedroom observations will only ever occur when there is another person present, when there is no intimate personal care being given and only if you agree to this. During observations, Ellice might also ask you some questions around drinking. Observations will be carried out during the day and night, at different times and on different days, for an extended period of time. This is so that Ellice gets to know the care home, and life within the care home, well. Ellice will check that you are happy to be observed, on each interaction. There might be times during the study, that you decide that you do not want to be observed. That is ok.

Ellice will also ask your care staff/ caregivers for some basic, personal information about you, such as how long you have lived in the care home, how much help you need in everyday living, your age and any health conditions. This might also involve getting information from your nursing records.

You might find it confusing or upsetting when Ellice is in your home. Ellice will understand if you ask her to leave and to stop asking questions. Ellice can also find someone you know well, to talk to, if you would like that. You might also consider speaking to friends or family or your GP.

Family caregiver/visitor, Health Professionals and Care Staff

If you are a **family caregiver or visitor, health professional or care staff**, we will ask if you are happy to take part in research observations. These observations will involve a researcher (Ellice) watching the usual daily routines

within the care home and taking some notes. Observations will usually happen within communal areas. Observations might also happen in bedrooms, for when residents spend more time in their bedroom. Bedroom observations will only ever occur when there is another person present, and when there is no intimate personal care being undertaken. During observations, Ellice might also ask you some questions around drinking. Observations will be carried out during the day and night. Observations will be carried out during the day and night, at different times and on different days, for an extended period of time. This is so that Ellice gets to know the care home, and life within the care home, well. Ellice will check that you are happy to be observed, on each interaction. There might be times during the study, that you decide that you do not want to be observed. That is ok.

Ellice will also invite you to take part in an interview about drinking and drinks provisions within the care home. The interview will be recorded and for up to one hour. You will be able to choose whether you would like these interviews face to face within a private room of the care home, or online via Microsoft Teams or Zoom. Ellice will be flexible in setting times to meet for the interview, so that it can be convenient for you. You might find that the interview raises certain emotions; if you feel emotional or upset at any time, you can choose to pause, or end the interview. If you need more support, please ask me (Ellice) for a chat. You might also consider speaking to friends or family, your GP, or other organisations offering support which you might prefer are:

- Samaritans: 116 123 24 hours a day, 365 days a year
or jo@samaritans.org
- SANEline: 0300 304 7000 (4.30pm-10.30pm)
- Dementia Connect: 0333 150 3456 and Dementia Talking Point Online

You are free to choose to take part or not. If you choose to take part, you will be asked to complete and sign a consent form. Even if you decide at that point, to take part, you are free to withdraw from the study and free to request that your data is withdrawn from the study, prior to analysis. If you want to withdraw from the study, please email ellice.parkinson@uea.ac.uk.

What are the possible benefits of taking part?

There are no direct benefits from taking part in this study.

I will be offering a free one-hour training session about drinking, to the care home. I will also offer family caregivers/ visitors a one-hour training session about drinking. You will be helping us to better understand drinking in care homes for residents living with memory difficulties.

What are the possible risks of taking part?

Being observed may be uncomfortable or distressing for some people. Some people may find some topics of conversations, or questions upsetting. If you experience being uncomfortable at any time, you can speak to me (Ellice) for a chat or seek support via the ways mentioned previously.

What will happen to the information collected from the observations and interviews (data)?

Your personal information will be anonymised, replacing it with a made-up name, so that you won't be identified. Your information will only be shared within the Research team at the University of East Anglia (Diane Bunn, Lee Hooper and Fiona Poland). No personally identifiable information will be used when reporting this study. The care home will also have a made-up name, and no identifying information about it reported. Personal information and participant contact information will be stored within password-protected files within the University's secure OneDrive server. Contact information will be destroyed at the end of the study. Hard copies of personal information and data will be stored within locked filing cabinets, within a locked room, which has restricted access. Any audio-recordings will be securely saved into a password-protected folder on the UEA OneDrive before I leave the care home, and then deleted off the audio-recorder. All data will be kept securely for 10 years, in line with the UEA Research Data Management Policy.

Data with identifying details removed, will be used within study reports, publications, presentations at conferences and on social media. We will also share the non-identifying findings with care homes, and public and patient involvement panels/networks.

You can provide additional consent to your anonymised data being shared for further research purposes. This will only happen if you give consent to it.

If I (Ellice) am worried by something that you say, which involves you or someone else being harmed, or at risk of being harmed, then I wouldn't be able to keep that confidential. At first, I would speak to you about it, and then I

would raise it with the care home manager and safeguarding via social services. It is my duty of care.

Would you like to take part?

If you would like to take part, please either contact Ellice on ellice.parkinson@uea.ac.uk or let the Care home manager/ staff know that you would like to take part. Ellice will then talk to you a little more, to ensure that you understand the study, and will then ask you to complete a consent form. If Ellice feels that you might not be able to understand all the information she's told you, then she will seek advice from someone who cares for you. Your caregiver will then complete a form, agreeing/not agreeing to your participation in the study.

Thank you for taking the time to read this information sheet. If you would like to speak to Ellice more about the research, or have any concerns, please contact her on ellice.parkinson@uea.ac.uk. Alternatively, you can raise any concerns with Diane Bunn (Ellice's supervisor) at d.bunn@uea.ac.uk.

The D-DRINC study is part of Ellice's PhD project at the University of East Anglia, which aims to explore and understand dehydration amongst older adults, with a particular focus on care home residents with memory problems. It is jointly funded by UEA, NIHR Applied Research Collaboration east of England and NHS South Norfolk and Suffolk CCG.

(The D-DRINC study was approved by the Camberwell St Giles Research Ethics Committee [REC Ref: 22/LO/0551] on 12th October 2022 and recorded by the Health Research Authority.)

GDPR Statement

How will I use information about you?

If you are a **care home resident**, then I will seek information from you, your caregiver and care staff and your nursing records, to be used within this study.

If you are a **caregiver/visitor, work in the care home, or a health professional**, then I will only seek information from yourself. I will not be accessing your health records for this study.

This information will include your name, age and health conditions. I will use this information to do the research study. Regulatory bodies might also check this information 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 be linked to a made-up name instead.

We (the research team) will keep all information about you safe and secure.

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

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, until the study reaches analysis stage, where everyone's data will be combined. At that point, we will be unable to untangle your data from anyone else's.
- We (the research team) need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you, once you have given it to the study.

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

You can find out more about how we (the research team) will use your information

- by visiting the D-DRINC study website: tinyurl.com/2p8hvskm
- by asking one of the research team: Diane Bunn d.bunn@uea.ac.uk
- by sending an email to ellice.parkinson@uea.ac.uk