

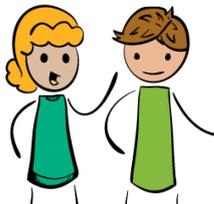
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

(for people living with a diagnosis of dementia)

Changed behaviours associated with memory and cognitive decline: Views and feelings of people living with dementia, families, and healthcare workers



This sheet has information about a study called **Changed behaviours associated with memory and cognitive decline: Views and feelings of people living with dementia, families, and healthcare workers.**



You can ask someone you know and trust to help you understand this sheet. First, we will introduce you to our team who are working on this study.



My name is Claire Burley. I am a research psychologist at the University of New South Wales Sydney.



My name is Anne-Nicole Casey. I am also a research psychologist at the University of New South Wales Sydney.



My name is Lynn Chenoweth. I am a Professor of Nursing at the University of New South Wales Sydney.



My name is Henry Brodaty. I am Scientia Professor of Ageing and Mental Health at the University of New South Wales Sydney. I am also Head of the Memory Disorders Clinic at the Prince of Wales Hospital.



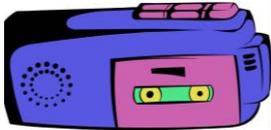
We want to learn how people feel about changed behaviours associated with memory and cognitive decline. We are inviting you because we want to find out the views of people who have been given a diagnosis of dementia. We also want to find out the views of one of your family members and a healthcare worker involved with your care.



Taking part in this study will involve you virtually meeting with Claire online or over the telephone. Claire will ask you some questions and ask you to talk about your views and feelings. She will ask you questions about changes you may have experienced and how you have been affected by the COVID-19 pandemic.



You can arrange the meeting with Claire to be the same time as your family member or carer if you would like. Though Claire will also speak to you both separately.



Claire will ask to record what you say though you can say no if you want to. No one else will listen to the recording and it will be destroyed shortly after the meeting. Claire will type up the recording though it will not be linked to your personal details so cannot be traced back to you.



The meeting will take approximately 1 hour. There will be refreshment breaks whenever you need. The meeting can end earlier or be longer if you would like it to.



You can choose what you would like to talk about. You do not need to answer any questions you do not want to.



We will keep your personal information private. No one will know the information we collect came from you.



We will write about what we find out. If you want, we will send you a summary of what we found out and ask for your feedback. If you need help to understand the summary or want to learn about the findings in more detail, the researchers can call you.



The researchers may share information from the study with other dementia professionals though this will not include any information that can be traced back to you.



You do not need to take part if you do not want to. You can also change your mind at any stage. If you choose to take part and then decide you do not want to, this is ok, just tell Claire.



If you would like to take part, you can sign the consent form. Or you can tell the researcher you are happy to take part over the phone. They can sign the form on your behalf. Remember you can change your mind and withdraw from the study at any point. This will not change the care you receive or your relationship with the university or hospital.



You can ask any questions when you like during the meeting. There are also some contact details for any other time.



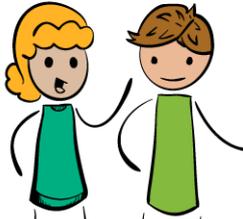
If you have any questions or want more information you can get in touch with the chief researcher:
Dr Claire Burley
Phone: +61 (0) 403 804 907
Email: c.burley@unsw.edu.au



If you want to complain about the study, you can get in touch with the research support office:
Phone: +61 (2) 9382 3587
Email: SESLHD-RSO@health.nsw.gov.au
It is their job to listen to you and find out what happened.
Tell them this number: *HREC*: 2019/ETH09814

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Please check each point below before you sign the consent form (or give verbal consent over the phone where the researcher will sign the form on your behalf). Write your initials in each box (or confirm with the researcher) on the right to show you understand:

	<p>I have read the sheet or had someone read it to me, so I understand. I understand what will happen during the study and why it is happening.</p>	
	<p>I was able to ask questions about what will happen. I was happy with the answers I was given.</p>	
	<p>I chose to take part in the study. No one is making me.</p>	
	<p>I know that I can change my mind at any time.</p>	
	<p>I know that Claire will collect information about me, but that she will keep my information private. Claire may share the information with other professionals. No one will know it was me who took part.</p>	
	<p>I know that I will be given a copy of this form to keep.</p>	

I WANT TO TAKE PART

Consent



I am signing this form or providing verbal consent because I understand what the study will involve, and I want to take part. I understand that you will only use my contact details to arrange for me to take part in the study and to tell me about the findings afterwards (if I want to be kept informed).

My name in capitals:	
My signature:	
Date:	
My phone number:	
My address:	
My email address:	
I would like to receive the study findings (please circle) YES NO	
Witness' name in capitals:	
Witness' signature:	
Date:	

I DON'T WANT TO TAKE PART ANYMORE

Consent



I am signing this form (or I have verbally requested the researcher to sign on my behalf) because I changed my mind. I do not want to take part anymore and I do not want you to use my details or what I said.

My name in capitals:

My signature:

Date:

Please send this form to:
Claire Burley
Dementia Centre for Research Collaboration
Level 3, AGSM Building
UNSW Sydney, Kensington
NSW 2052