

ONLINE PARTICIPANT INFORMATION STATEMENT

Forward with Dementia Website Email Subscription
Scientia Professor Henry Brodaty

1. What is this this subscription about?

The Forward with Dementia website is part of a larger research project that aims to improve life in the 12-months after a diagnosis of dementia. The website is for people living with dementia, their families, carers or supporters, as well as health and social care practitioners.

This subscription is simply to collect the names (real or nicknames) and email addresses of visitors to the Forward with Dementia website to allow us to send you:

- website updates,
- invitations to webinars and other educational activities, and
- to send an invitation to participate in an evaluation of the website in the future.

You have been invited to subscribe because you recently used the Forward with Dementia website.

2. Who is involved in this website?

The website has been produced as part of a larger research project which is being carried out in Australia by Professor Henry Brodaty and Dr Meredith Gresham from the University of NSW, Professors Lee-Fay Low, and Yun-Hee Jeon from the University of Sydney, A/Prof Lyn Phillipson from the University of Wollongong and an advocate and person living with younger onset dementia, Ms Kate Swaffer from Dementia Alliance International. We are part of a larger international collaboration which includes Alzheimer's Disease international and the World Health Organisation.

In Australia, our work is funded by the Australian Government's National Health and Medical Research Council.

3. What am I signing up to?

Before you decide to subscribe to the Forward with Dementia website we need to ensure that you understand what you are signing up to. If you subscribe by providing your name (real or nickname) and email address, we will send you website updates and an invitation to participate in evaluating this website in the future. We anticipate we will send update emails approximately every 2-4 weeks.

4. Do I have to subscribe?

Subscription is voluntary. If you do not want to subscribe, you do not have to. You can unsubscribe at any time and your name and email will be removed from the list.

5. What does subscription require, and are there any risks involved?

Subscription requires you to simply click on the link and enter your name and email. There are no foreseeable risks involved in subscribing, and you can unsubscribe at any time.

6. What are the possible benefits to subscription?

The possible benefits of subscribing will be that you will receive reliable, up-to-date information about dementia and new content on the website. You will receive information about educational events that may be of interest, such as webinars with experts. However, we cannot promise any particular benefits from website use.

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7. What will happen to information about me?

By subscribing, you are providing your permission for the research team to collect your name and email address and send you website updates and invitations to educational events and future research.

Your name and email address will be collected using the secure Mailchimp server which is located in the USA. The research team will be able to see your name and email but will not share your name or email with anyone else. We will securely store the name and email database for a minimum of five years after any publications about the larger study. If you unsubscribe your name and email address will be removed from the list and you will not be emailed again.

8. How can I find out more about the larger study?

If you would like to read about the larger study about improving communication of dementia diagnosis and support in the 12-months following diagnosis please go to <https://cheba.unsw.edu.au/consortia/cognisance>

9. What if I want to unsubscribe?

If you have subscribed, you may unsubscribe at any time. You do this by clicking 'unsubscribe' at the bottom of any email we send you. If you decide to unsubscribe, the researchers will delete your name and email address from our database, and you will not receive any further emails. Your decision to unsubscribe will not affect your ability to access or use the Forward with Dementia website, or any relationship with the research team, or the universities of NSW, Sydney or Wollongong.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

10. What should I do if I have further questions about my involvement?

The person you may need to contact will depend on the nature of your query. If you require further information or if you have any problems which may be related to your subscription to Forward with Dementia, you can contact the following member of the research team:

Research Team Contact

Name	Dr. Meredith Gresham
Position	Research Co-ordinator
Telephone	02 9385 2597
Email	m.gresham@unsw.edu.au



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11. What if I have a complaint or any concerns?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC210308

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Consent Form – Participant providing own consent

Declaration

By submitting my name (real or nickname) and email address:

- I understand I am consenting to receive emails containing updates to the website and invitations to future events and research;
 - I have read and understand the information above;
 - I provide my consent for my email address and name (real or nickname) to be used for the purpose of this database only;
 - I understand that if necessary, I can ask questions and the research team will respond to my questions;
 - I freely agree to subscribe to this website and understand that I am free to unsubscribe at any time and this will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form from <https://www.forwardwithdementia.org/au/newsletter-sign-up/>.

You are providing your consent by clicking the "subscribe now" button on the newsletter page.