National Centre of Excellence in Intellectual Disability Health

UNSW SYDNEY

Participant Information and Consent Form

Living with dementia: Experiences of people with intellectual disability and their supporters

This form is for supporters of people with intellectual disability living with dementia.

A supporter might be a family member, friend, partner, or volunteer carer for a person with intellectual disability living with dementia.

This sheet has information about research called ‘Living with dementia: Experiences of people with intellectual disability and their supporters’.

Research means finding out what people think about things and using the information to help other people.

We are doing this research to understand the experiences of people with intellectual disability living with **dementia** and their supporters.

Dementia is a health problem. It is caused by changes in the brain.

You can ask someone you trust to help you understand this sheet.

Who is doing the research? What is it about?



My name is Rachael Cvejic. I am a researcher at the University of New South Wales.

I am working with Simone Reppermund, Julian Trollor, Tom Morris, and Janelle Weise.



We want to find out about the experiences of supporters of people with intellectual disability living with dementia.



We want to find out what supporters of people with intellectual disability living with dementia want and need.

What does taking part involve?



Screening questions
We will ask you some questions to check if you can take part in the research.

We will ask you the questions over the phone.



If you cannot take part in the research we will destroy any information collected about you.



If you can take part in the research we will find a day and time for an interview.



Interview
Taking part involves answering some questions.

The interview can be

- in person



- on the phone



- or online.



We will ask you about:

- Your experience supporting a person with intellectual disability living with dementia
- What has helped you as a supporter
- What has been hard for you as a supporter.



You can choose which questions to answer.

You can say no if you don't want to answer a question.



We will ask to record what you say. If you don't want us to, that is OK. We will take notes instead.



The research will take up to 1 hour.



If you want to meet in person we will meet you at a place you choose. It could be

- A private room at the National Centre of Excellence in Intellectual Disability Health in Randwick, NSW



Or

- Your home.



If you want to, you can bring someone you trust to help you.



We will contact you again about one month after the interview.

We will check if you are happy with what you said in the interview.



You will get a $100 gift card to say thank you.

Do I have to take part?



You only have to take part if you want to.

You can say no. It's your choice. No one will be angry if you say no.

Even if you say yes, you can change your mind later and stop taking part.

What will happen to my information?



We will store your information at the National Centre of Excellence in Intellectual Disability Health for at least 5 years.

We will keep your information private.

We will not tell anybody your name or where you live.

No one will know it was you who took part.



We will write about what we find out. If you want, we will send you a summary.

Who can I get in touch with about the research?



If you have any questions, get in touch with
Rachael Cvejic
Phone (02) 9065 1625
Email r.cvejic@unsw.edu.au



If you want to complain about the research, you can get in touch with the Human Research Ethics Coordinator. It is their job to listen to you and find out what happened.
Phone (02) 9385 6222
Email humanethics@unsw.edu.au
Tell them this number HC10651



If you feel upset after taking part, you can talk to some who supports you or call
Beyond Blue on 1300 22 4636

- for support and information about mental health

National Dementia Helpline on 1800 100 500

- for support and information about dementia.

I want to take part

FOR INTERVIEWS

Living with dementia: Experiences of people with intellectual disability and their supporters

I am signing this form because I understand about the research and I want to take part.

My signature: _____

Date: _____

My phone number: _____

My address: _____

My email address: _____

I understand that you will only use my contact details for me to take part in the research and to tell me about the findings afterwards.

Witness signature: _____

Date: _____

A witness is someone who saw you sign the form.

I don’t want to take part anymore

Living with dementia: Experiences of people with intellectual disability and their supporters

I am signing this form because I changed my mind. I don’t want to take part anymore and I don’t want you to use what I said.

My signature: _____

Date: _____

Witness signature: _____

Date: _____

A witness is someone who saw you sign the form.

Send this form to:

Rachael Cvejic
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UNSW Health Translation Hub
55 Botany Street, Randwick NSW 2031
Email: r.cvejic@unsw.edu.au