

# Living with Dementia in Aotearoa/ New Zealand

LITMUS



# Where I am today



Hadleigh Lodge Hamilton



# Where I live



# Overview of webinar

- A little about me
- How we did the research
- Challenges we faced
- The research findings
- How the research is being used

**Oxford**



**Wellington**



**Belfast**



**Smith family at Castlepoint**



# Understanding the lives of people living with dementia

- What are their experiences through the dementia journey?
- What support and services are used or not available?
- How do people live well in their community?
- What is the effect on relationships with family, friends, community?

Thank  
you!

# Why did we get involved?



It is personal

Research processes can silence voices





# People with dementia are demanding to be heard

- Involve at all stages
- Value their knowledge
- Ensure safe and secure environment
- Keep communication clear and not stigmatising
- Be dementia aware
- Keep to 'dementia time' not researcher time

Ethics processes can create barriers to inclusion

Should social researchers assess cognitive capacity to consent to take part in lived experience research?

# Older Adults' Capacity to Consent to Research Scale

- What is the purpose of the research?
- Tell me some things you may be asked about?
- What are the things worrying you about the research?
- If you don't want to, do you have to take part in the research

# Everyone's right to consent

- Research processes need to be inclusive
- Capacity to Consent to Research Scale - a universal tool

# This is our story

He aha te mea nui o te ao

He tangata, he tangata, he tangata

What is the most important thing in the world?

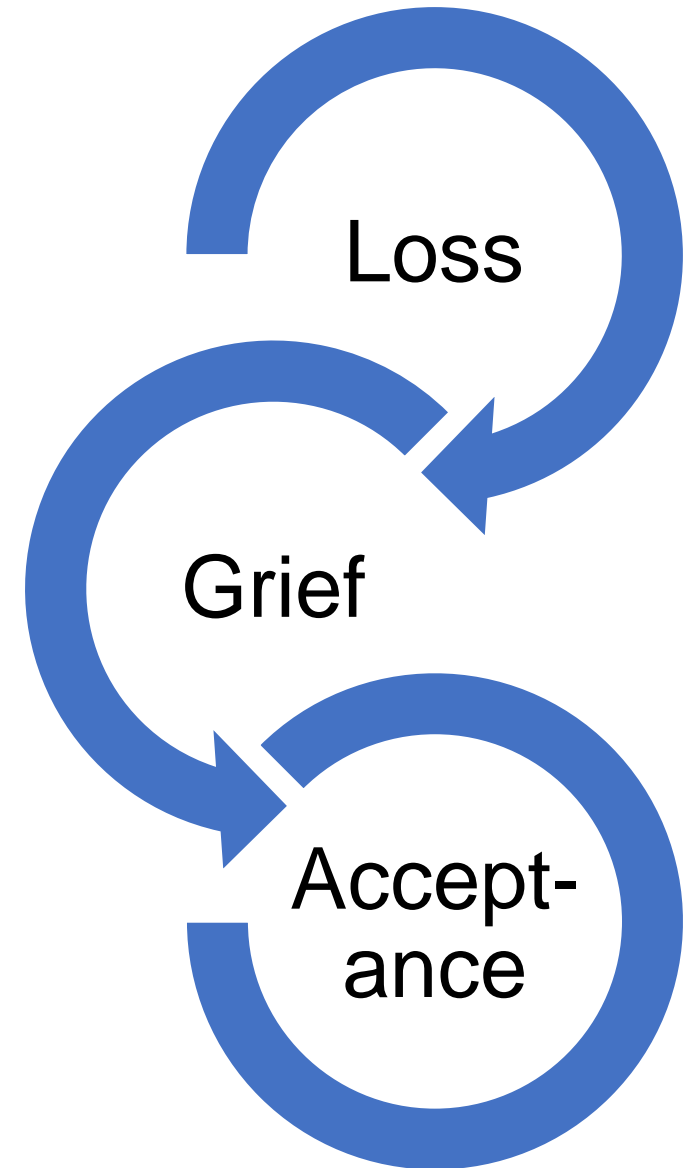
It is the people, it is the people, it is the people

*Māori proverb*

# People living with dementia have diverse lives

Varied experiences by

- Age
- Gender
- Ethnicity
- Symptoms and stage
- Support received
- Income
- Personal preferences



People with dementia are forgetful and intelligent

Person with dementia:

I don't think I've lost my intellect. I follow the news. I've always **been a thinker** and I still am.

But, not everyone sees this:

A lot of people **treated me differently** and that made it harder. And I thought, I'm just a normal person really. Yeah, **I felt like I was really dumb.**

# People with dementia want a say in their lives

- They value their independence
- They appreciate the need to balance independence and safety, to reassure family
- Some feel they have little control over their life choices

I still want **some control over my affairs** and how things are done...The kids are more inclined to tell me what I should be doing. And **sometimes I don't take their advice** after thinking it through, and they have had to **learn that's ok** too.



# With some changes, people with dementia live meaningful lives

Society sees people with dementia by stigmatised view

The idea of meaningful life can seem strange

People with dementia advised:

- best not to worry
- accept the diagnosis
- keep active and engaged

Jumping out of  
my comfort zone  
– Sky Tower  
bungy



But, living a meaningful life with dementia is not easy

The one thing that I would really emphasise is that **whilst the diagnosis is traumatic**, and it is very traumatic... We believe, you can go on and **live a meaningful life with some changes.**

# Getting a diagnosis is difficult

People delay seeking medical advice

A crisis or family prompt a visit to the GP

Difficult 12 months or more trying to get a diagnosis

People have varying GP experiences

[After diagnosis] The **GP signed me off** – more or less. He didn't want to see me anymore and just gave me some pills and said '**there you go, not much we can do here**. You're not as bad as some, keep taking the pills and if it gets worse, come see us again'.

# Being diagnosed with dementia is a fearful time

I'll never forget the day walking out of the office and to the car. We were **just stunned** ... when you think of the **word Alzheimer's**, you think of **last stages**. And that's a picture that people will have.

You're given the impression well, **go home and put your affairs in order and wait**. We felt that was what was going happen to us. Go home, get your affairs in order, and **that's it**.

# People living with dementia need access to a range of services

- Care partners are the main source of support
- Access daily living services, socialising and connecting services, support groups, and education sessions
- But it is difficult
  - Don't know what is available
  - Reach crisis before taken seriously
  - Services vary across New Zealand
  - Service do not diverse needs
  - Lack of respite care

# Care partners feel love, loss and guilt

- Care partnership is based on love and commitment
- Care partners have a sense of loss for the person they knew and the life they had
- Care partners' stress increases with the progression of the dementia
- Care partners need support to maintain their wellbeing
- Care partners feel relief and guilt when the person with dementia moves into residential care

# People with dementia can live better lives

- Understand dementia, respect and include them in their lives
- Support through difficult times
- Time, information and support to make their decisions
- More health and support services tailored to their diverse needs
- Support for their care partners



# Dementia declaration

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- Invest in prevention
- Improve diagnosis and support
- Provider services to support people to live at home
- Provide flexible, high quality respite services
- Build age and dementia friendly communities
- Monitor progress



**Nā reira, nāu te rourou,  
nāku te rourou, ka ora ai te  
iwi.**

With your food basket and my  
food basket the people will  
thrive

**LITMUS**



# Litmus research team

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# Links to reports

You will find the research report here:

<https://www.alzheimers.org.nz/our-voice/new-zealand-data/lived-experience-of-dementia-research>

You will find the dementia declaration here:

<https://www.alzheimers.org.nz/our-voice/dementia-declaration>

Liz Smith

<https://litmus.co.nz/>



<https://www.alzheimers.org.nz/>

