

Technical Appendices: Evaluation of services for people living with dementia provided by four local Alzheimers organisations

Prepared for:
Alzheimers New Zealand

14 April 2021

Contents

Appendix 1: Evaluation Advisory Group members	2
Appendix 2: Detailed methodology	3
Appendix 3: Evaluation tools	9

Appendix 1: Evaluation Advisory Group members

Name	Organisation	Role
Alister Robertson	Alzheimers New Zealand	Consumer Advisory Group
Rose Love	Alzheimers New Zealand	Consumer Advisory Group
Dr Kathy Peri	Auckland University	Academic
Glenn Bradley	Alzheimers Tauranga	Service provider
Diane Tolley	Alzheimers Society Marlborough	Service provider

Evaluation Advisory Group – ex-officio members

Name	Organisation	Role
Liz Smith	Litmus	Partner: Project Lead
Stephen Lungley	Alzheimers New Zealand	Advisor
Jean Gilmour	Alzheimers New Zealand	Advisor

Appendix 2: Detailed methodology

We used safe and inclusive evaluation approaches

People living with dementia, care partners, advocates, and researchers have identified safe and inclusive practices for research on dementia (The Scottish Dementia Working Group Research Sub-group, 2014; Wilkinson & Novak, 2017; Dementia Engagement and Empowerment Project (DEEP) Guides, 2014).

We followed the Scottish Dementia Working Group Research Subgroup principles for research with people with dementia.

These are:

- involve, value, and keep informed people with dementia about the research at all stages (including design, analysis, and reporting)
- recognise and value the knowledge of people with dementia
- ensure a safe environment for people participating in research
- keep communication and language clear and simple, and avoid stigmatising language
- be dementia-aware by knowing about dementia, being empathic and respectful, and allowing time for people to think and reflect
- keep to 'dementia time' not researcher time (i.e., be flexible about the best time to talk, keep to agreed timeframes, remind people about the interview, recap previous conversations).

Our survey and interview approach and response rates

We surveyed people living with dementia

We surveyed people who use the services provided by four local Alzheimers organisations. The survey asked people about their experience accessing and using services from their local organisation.

We sent a survey to everyone listed as a service user in each local organisation. We distributed the survey online and on paper. We received 291 responses to the survey.

- In Tauranga/Western Bay of Plenty, we emailed service users with email contact information and posted a paper copy of the survey to people without an email address.
- In Nelson, we emailed the survey to service users with email access and sent a paper copy to people without an email address.
- In Manawatū, staff handed out paper copies of the survey to people who attended the day programme (when services restarted after lockdown).
- In Eastern Bay of Plenty, we posted a paper survey to all service users.

Table 1 below provides the total responses from each location.

Table 1: Number of survey responses across the four locations

Location	People with dementia	Care partners	Response type Unknown	Total
Nelson	13	44		57
Manawatū	32	36	1	69
Eastern Bay of Plenty	12	16		28
Western Bay of Plenty	25	110		135
Location unknown	-	2		2
Total	82	208	1	291

We estimate a 20 percent response rate to the survey

We do not know the total number of people who received the survey as the local Alheimers organisations distributed the survey. We have estimated the response rate to be around 20 percent based on the number of households who received the survey at each location (Table 2).

Table 2: Estimated Response rates across the four locations

Location	Approx. number of households sent a survey¹	Number of people completed survey	Response rate
Nelson	270	57	23%
Manawatū	360	69	19%
Eastern Bay of Plenty	132	28	21%
Tauranga/Western Bay of Plenty	350	135	39% ²

We achieved a reasonable range of people completing the survey

Table 3 below details the profile of people who completed the survey by ethnicity, gender, age, and income.

¹ In each location we sent the survey to service users' households. Households may include a person with dementia who lives alone or a care partner and person with dementia.

² The high response rate for Tauranga/Western Bay of Plenty is because we have calculated by household and not by service users. In Tauranga/Western Bay of Plenty most responses were from care partners.

Table 3: Overview of the sample profile achieved across the four locations

Profile type	Nelson	Manawatū	Eastern Bay of Plenty	Western Bay of Plenty
Total responses by location	57	69	28	135
Response type³				
Person with dementia	13	36	12	25
Care partner	44	32	16	110
Ethnicity⁴				
Māori	2	6	9	7
Pākehā	49	64	19	123
Other	7	2	1	7
Gender				
Female	32	38	17	100
Male	25	31	11	34
Age				
Under 65	6	9	6	26
65-84	41	44	15	67
85 and over	5	16	5	12
Individual income				
Under \$30,000	26	37	15	43
\$30,000-\$49,999	20	13	8	37
\$50,000 or more	5	4	2	30

³ One person in Manawatū did not identify themselves as either a care partner or person with dementia.

⁴ Ethnicity, age and income may be greater or smaller than the number of people who completed the survey. Some people identify with more than one ethnicity. Some people did not answer the age and income questions.

We interviewed service users and people who deliver the services

We conducted qualitative interviews with people with dementia, care partners and in pairs (a care partner and a person with dementia). Care partners were more likely to take part in an interview.

We interviewed 15 people involved in delivering services. We interviewed between two and six staff members, board representatives or volunteers from each of the participating locations.

Our achieved sample is in the table below.

Table 3: Number of people who participated in an evaluation interview

Location	People with dementia	Care partner	Unit	Stakeholders	Total
Nelson	5	5	2	4	12
Manawatū	2	3	2	4	6
Eastern Bay of Plenty	1	5		2	6
Western Bay of Plenty	2	4		5	6
Total	10	17	4	15	30

All interviews were conducted by phone or online based on participant preference. Interviews were around 30 minutes to one hour long and were recorded.

We followed a multi-stage thematic analysis process

We manually added the paper survey responses to a excel spreadsheet. The data was then checked for errors. We combined the paper survey responses with the online responses and developed data tables to analyse the survey responses. We analysed the survey data by response type, location and all questions.

We transcribed the interviews. Where requested, we sent people their transcripts to review. We conducted thematic analysis across the interview transcripts. We searched for common themes and key points and noted divergent opinions and experiences.

We triangulated the findings across the survey and the interview data to identify the key findings. We then presented these key findings and themes to the evaluation advisory group for feedback and discussion.

We developed the report based on these analytical discussions. We sought feedback from the participating organisations and the evaluation advisory group at the draft report and final report stage.

Appendix 3: Evaluation tools

Survey for people with dementia using Alzheimers member organisation services

First, we want to ask some questions about you

1. Which of the following best describes who is answering the questions?

- I am a person with dementia
- I am a family member or support person and I am helping a person with dementia to complete the survey

2. Which region do you live in?

- Western Bay of Plenty (Tauranga)
- Eastern Bay of Plenty (Whakatāne)
- Manawatū
- Nelson

3. Are you male or female?

- Male
 - Female
 - I prefer to self-describe
-

4. How old are you?

5. What is your ethnicity (tick as many as appropriate)

- Māori
 - Pākehā (New Zealand European)
 - Samoan
 - Cook Island Māori
 - Tongan
 - Niuean
 - Chinese
 - Indian
 - Other
-

6. What is your annual income (remember, this survey is anonymous)?

We are asking this question to help us understand whether people with more financial resources have better access to services.

- \$0 – \$10,000
- \$10,001 - \$20,000
- \$20,001 - \$30,000
- \$30,001 - \$40,000
- \$40,001 - \$50,000
- \$50,001 - \$60,000
- \$60,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 - \$150,000
- More than \$150,000

Now we want to ask some questions about the services or support you received from your local Alzheimers organisation

7. How did you first hear about your local Alzheimers organisation?

- My GP told me about the organisation
- A friend or family/whānau member told me about them
- My partner/spouse searched for support organisations
- I searched online for dementia support organisations in my area
- Another health provider told me about them
- I found out another way

Please tell us how

8. How long have you been accessing support from your local Alzheimers organisation?

9. What kind of support do you receive from your local Alzheimers organisation? (you can tick as many as you want)

- They help me make a support plan
 - I attend the day programmes they run
 - I attend education programmes they run
 - I receive cognitive stimulation therapy from them
 - Advisors visit me
 - They help me get appointments with a specialist or someone else
 - They connected me to clubs and other groups
 - They give me information about dementia and the services available
 - They give my family or spouse information about dementia
 - They support me another way
- Please tell us how _____

10. On average, how often are you in contact with your local Alzheimers organisation for services or support?

- Every weekday
- A few times a week
- Once a week
- A few times a month
- Once a month
- Once every few months
- Once a year

11. Do you get dementia-related support from other services?

Yes

No

If yes, where else do you get support?

Now we want to ask some questions about your experiences of the support your local Alzheimers organisation provides

12. People living with dementia can access support and services from local Alzheimers organisations. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
I know about the support and services available from my local Alzheimers organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to access support from my local Alzheimers organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan outlining what to do in an emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
Services and support my local Alzheimers organisation offers meet my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
The information tells me what I need to know about living with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information is relevant to my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information helps me understand how dementia affects everyday life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get more information about living with dementia as my situation changes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Staff and volunteers provide services and support in local Alzheimers organisations. How much do you agree or disagree with the following sentences?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
People who support me are respectful and treat me with dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff and volunteers listen to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel comfortable talking to staff and volunteers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff and volunteers are knowledgeable about dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. How did you feel about the services and support you received? How much do you agree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
I make decisions about the type and level of services and support I receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The service respects my cultural or spiritual values and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can choose the support that suits me best	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
The service helps me connect to people with similar interests and in a similar position to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. Alzheimers New Zealand member organisations support people with dementia to live well and independently in their communities. How much do you agree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
Support from my local Alzheimers organisation helps me live more independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from my local Alzheimers organisation helps me feel more connected with my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We want to hear about support people received during lockdown in New Zealand

17. Since the start of the COVID lockdown (26 March 2020), what support have you received from your local Alzheimers organisation?

- They helped me make a support plan over the phone or online
- They phoned me to see how I was
- They phoned a family member supporting me to see how they were
- They have emailed or posted me updates about COVID-19 and other information
- They have set up online groups for me to join
- They worked with me to set up my online access so I can see family/friends
- They provided online activities for me
- They have provided activity packs for me
- They supported me another way

Please tell us how

18. Thinking about the services and support you received during lockdown from your local Alzheimers organisation, how important is this support to help you live well with dementia?

- Very important
- Quite important
- Somewhat important
- Not at all important
- Don't know

19. What other support would have been helpful for you to live well with dementia during lockdown?

Thinking about the support and services your local Alzheimers organisation provides overall

20. How important is this support to help you live well with dementia?

- Very important
- Quite important
- Somewhat important
- Not at all important
- Don't know

21. How can your local Alzheimers organisation improve their support and services?

22. Is there support or services from your local Alzheimers organisation that you would like to get to help you live well that is not currently available?

Yes No

If yes, please tell us what support you would like to see.

Thank you for completing this survey!

Please put your completed survey in the pre-addressed envelope provided and post it to Litmus.

Survey for care partners and family of people with dementia using Alzheimer organisations services

First, we want to ask some questions about you

1. Which region do you live in?

- Western Bay of Plenty (Tauranga)
- Eastern Bay of Plenty (Whakatāne)
- Manawatū
- Nelson

2. Are you male or female?

- Male
 - Female
 - I prefer to self-describe
-

3. How old are you?

4. What is your ethnicity (tick as many as appropriate)

- Māori
 - Pākehā (New Zealand European)
 - Samoan
 - Cook Island Māori
 - Tongan
 - Niuean
 - Chinese
 - Indian
 - Other
-

5. What is your annual income (remember, this survey is anonymous)?

We are asking this question to help us understand whether people with more financial resources have better access to services.

- \$0 – \$10,000
- \$10,001 - \$20,000
- \$20,001 - \$30,000
- \$30,001 - \$40,000
- \$40,001 - \$50,000
- \$50,001 - \$60,000
- \$60,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 - \$150,000
- More than \$150,000

Now we want to ask some questions about the services or support you received from your local Alzheimers New Zealand member organisation

6. How did you first hear about your local Alzheimers organisation?

- My GP told me about the organisation
- A friend or family/whānau member told me about them
- My partner/spouse searched for support organisations
- I searched online for dementia support organisations in my area
- Another health provider told me about them
- I found out another way

Please tell us how

7. How long have you and your partner/spouse or family member been accessing support from your local Alzheimers organisation?

8. What kind of support do you receive from your local Alzheimers organisation? (you can tick as many as you want)

- They supported me and my family member with dementia when we first heard she/he may have dementia
- They helped my family member with dementia and me make a support plan
- I have a break while my family member with dementia attends their programmes or events
- I attend a care partner support group they facilitate
- I attend care partner programmes
- My family member with dementia attends education programmes they run
- My family member with dementia receives cognitive stimulation therapy from them
- Advisors visit me and my family member with dementia
- They have helped my family member with dementia get an appointment with a specialist or someone else
- They give me information about dementia and the services available
- They give my family member with dementia information about dementia
- They support me another way

Please tell us how _____

9. On average, how often do you interact with your local Alzheimers organisation for services or support?

- Every weekday
- A few times a week
- Once a week
- A few times a month
- Once a month
- Once every few months
- Once a year

10. Do you get dementia-related support from other services?

- Yes
- No

If yes, where else do you get support?

Now we want to ask some questions about your experiences of the support your local Alzheimers organisation provides

11. People living with dementia can access support and services from local Alzheimers organisations. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
I know about the support and services available from my local Alzheimers organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to access support from my local Alzheimers organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan outlining what to do in an emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services and support my local Alzheimers organisation offers meet my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Alzheimers New Zealand member organisations often give people information about living with dementia. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
The information told me what I needed to know to support my family member/friend living with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information was relevant to my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information helped me understand how dementia affects everyday life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get more information about living with dementia as my situation changes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Staff and volunteers provide services and support in local Alzheimers New Zealand member organisations. How much do you agree or disagree with the following sentences?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
People who support me are respectful and treat me with dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff and volunteers listen to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel comfortable talking to staff and volunteers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff and volunteers are knowledgeable about dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. How did you feel about the services and support you received? How much do you agree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
The service respects my cultural or spiritual values and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner and I can choose the support that suits us best	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
The service helps me connect to people with similar interests and in a similar position to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Alzheimers New Zealand member organisations support people with dementia and their families to live well and independently in their communities. How much do you agree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree	I don't know
Support from my local organisation helps us live more independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from my local organisation helps us feel more connected with my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from my local organisation helps me support my partner with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We want to hear about support people received during lockdown in New Zealand

16. Since the start of the COVID lockdown (26 March 2020), what support have you received from your local Alzheimers New Zealand member organisation?

- They helped us make a support plan over the phone or online
- They phoned me to see how I was
- They phoned my family member with dementia to see how they were
- They have emailed or mailed me updates about COVID-19 and other information
- They provided online activities for me
- They have provided activityg packs for me
- They have set up online support groups for me to join
- They worked with me to set up my online access so I can see family/friends
- They supported me another way

Please tell us how

17. Thinking about the services and support you received during lockdown from your local Alzheimers organisation, how important is this support to help you live well with dementia?

- Very important
- Quite important
- Somewhat important
- Not at all important
- Don't know

18. What other support would have been helpful for you to live well with dementia during lockdown?

Thinking about the support and services your local Alzheimers organisation provides overall

19. How important is this support to help you live well with dementia?

- Very important
- Quite important
- Somewhat important
- Not at all important
- Don't know

20. How can your local Alheimers organisation improve their support and services?

21. Is there support or services you would like to get that is not currently available in your region?

Yes No

If yes, please tell us what support you would like to see.

Thank you for completing this survey!

Please put your completed survey in the pre-addressed envelope provided and post it to Litmus.

Older Adults' Capacity to Consent to Research (OACCR) Checklist⁵

Name:

Address:

Question	Yes	No
1) What is the purpose of the evaluation?		
2) Tell me some things you may be asked about?		
3) What are the things that might worry you about taking part in the evaluation?		
4) If you don't want to, do you have to take part in the evaluation?		

⁵ See Lee, M. (2010). The capacity to consent to research among older adults, *Educational Gerontology* 36(7): 592–603. doi:10.1080/03601270903324461

Assessment:

Informed consent as answered appropriately all four questions	
Supported decision making as participants can answer only questions 1 and 4.	
Exclusion as participant cannot answer questions 1 and 4.	

Commentary on assessment

Actions taken if exclusion

Other information

Discussion Guides: Person living with dementia, Care Partner, Unit interview

These guides give an overview of discussion areas. We use a flexible interview approach so people can talk about other relevant topics. We may not talk about all areas below in an interview and that's fine.

Person with Dementia

Introduction

- Introduce self/Litmus
- Evaluation background and purpose
- Informed consent/supported decision-making
- Time: around one hour; breaks if needed; come back to complete if needed
- Other needs?

Engagement with the Alzheimers New Zealand member organisation

1. Please can you tell me how you first got involved with Alzheimers New Zealand member organisation in your area
 - When and how did you first start using their services?
Probe: How did you hear about them? Did they contact you? Did you contact them? Care Partner contact?
 - What other support or services do you receive to help you live well with dementia?
Probe: Family and peer support, dementia friends, respite care

Alzheimers New Zealand member organisation support and services

2. Tell me about the support and services you receive from your local member organisation?
 - What support or services have you received?
 - How easy was it to get the support and services you needed?
 - How useful is the support or services they provide for you? For your care partner?
 - What kind of support was useful? Why?
 - What support was not useful? Why?
 - How, if at all, has the support you received changed with the Covid-19 restrictions?
 - How well do/did Alzheimers New Zealand meet your needs and help you live well?
 - Before the Covid-19 restrictions? After the restrictions?
 - How culturally appropriate is the support or services you receive? What makes it culturally appropriate?

Improvements to the services Alzheimers New Zealand member organisations provide

3. How could your local member organisation improve the services or support they provide you?
 - What services or support do you think they provide really well?
 - What do you think they are not doing so well?
 - How could they better support you and your care partner to live well?
 - What other services or support would be helpful?

Close interview

Thanks for time, koha, next steps.

Person living with dementia and care partner

Introduction

- Introduce self/Litmus
- Evaluation background and purpose
- Set expectation want to hear from both people
- Informed consent/supported decision-making
- Time: around one hour; breaks if needed
- Other needs?

Engagement with the Alzheimers New Zealand member organisation

1. Please can you tell me how you first got involved with the Alzheimers New Zealand member organisation in your area
 - When and how did you first start using their services?
Probe: How did you hear about them? Did they contact you? Did you contact them?
 - What other support or services do you receive to help you live well with dementia?
Probe: Family and peer support, dementia friends, respite care

Alzheimers New Zealand member organisation support and services

2. Tell me about the support and services you receive from your local Alzheimers member organisation?
 - What support or services have you received?
 - How easy was it to get the support and services you needed?
 - How useful is the support or services they provide for you both?
 - What kind of support was useful? Why?
 - What support was not useful? Why?

- How, if at all, has the support you received changed with the Covid-19 restrictions?
- How well do/did Alzheimers New Zealand meet your needs? Before the Covid-19 restrictions? After the restrictions?
- How culturally appropriate is the support or services you receive? What makes it culturally appropriate?

Improvements to the services Alzheimers New Zealand member organisations provide

3. How could your local member organisation improve the services or support they provide you?
 - What services or support do you think they provide really well?
 - What do you think they are not doing so well?
 - How could they better support you both? Individually? As a partnership?
 - What other services or support would be helpful?

Close interview

Thanks for time, koha, next steps.

Care partner interview

Introduction

- Introduce self/Litmus
- Evaluation background and purpose
- Informed consent/supported decision-making
- Time: around one hour; breaks if needed
- Other needs

Engagement with the Alzheimers New Zealand member organisation

1. Please can you tell me how you first got involved with the Alzheimers New Zealand member organisation in your area?
 - When and how did you first start using their services? Probe: How did you find out about them? Did they contact you? Did you contact them?
 - What other support or services do you receive to help you live well with dementia? Probe: Family and peer support, dementia friends, respite care

Alzheimers New Zealand member organisation support and services

2. Tell me about the support and services you receive from your local Alzheimers member organisation?
 - What support or services have you received?
 - How easy was it to get the support and services you needed?
 - How useful is the support or services they provide for you? For the person living with dementia?
 - What kind of support was useful? What was not useful? Why?
 - How, if at all, has the support you received changed with the Covid-19 restrictions?

- How well do/did your Alzheimers member organisation meet your needs? Before the Covid-19 restrictions? After the restrictions?
- How culturally appropriate is the support or services you receive? What makes it culturally appropriate?

*Prompt: How do Alzheimers organisation services fit with respite care?
To what extent is it respite care for you?*

Improvements to the services Alzheimers New Zealand member organisations provide

3. How could your local member organisation improve the services or support they provide you?
 - What services or support do you think they provide really well?
 - What do you think they are not doing so well?
 - How could they better support you and your partner?
 - What other services or support would be helpful?

Close interview

Thanks for time, koha, next steps.

Discussion Guide: Alzheimers New Zealand stakeholders

Introduction

- Introduce self/Litmus
- Evaluation background and purpose
- Informed consent, audio-recording, confidentiality
- Time: around one hour
- Other needs

Your role with Alzheimers New Zealand

1. Please tell me about your role with the Alzheimers New Zealand member organisation.
 - How long have you been working for/volunteering with your local member organisation?

Alzheimers New Zealand member organisation support and services

2. Tell me about the support and services your member organisation provides in your region?
 - How do people access support?
 - How is support changing?
 - What is working well or not so well with the support you provide?
 - What are the challenges in providing support? What enables you to do well?
 - How culturally appropriate is the support or services you provide? What makes it culturally appropriate?
 - How well do you think your member organisation is meeting people's needs? Why? Why not?
 - What needs are not being met?

3. What has changed with the Covid-19 restrictions?

- What has been the impact of these changes for you/your staff/the services you provide?
- What has been the most significant change?

Improvements to the services member organisations provide

4. How could your member organisation improve the services or support you provide?

- What services or support do you think your region is providing really well?
- What do you think could be improved?

Close interview

Thanks for time, next steps.