

To return questionnaire to
participant Yes No

QUESTIONNAIRE FOR INFORMAL CARER



KAI ĀWHINA (LOVE & Support) STUDY

Life and Living in Advanced Age:
A Cohort Study in New Zealand

Te Puāwaitanga o Ngā
Tapuwae Kia Ora Tonu

~ WAVE 4 ~

This questionnaire has been developed by the LiLACS NZ research team and is for the purpose of the LiLACS NZ project. For queries please contact Professor Ngaire Kerse at the LILACS NZ research base.

Professor Ngaire Kerse
Department of General Practice and Primary Health Care,
School of Population Health
University of Auckland
Private Bag 92019, Auckland, New Zealand
ph 64 9 3737599 ext 84467, fax 64 9 3737624, e-mail n.kerse@auckland.ac.nz

Date:

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(dd) (mm) (yyyy)

Start Time: (24 hour time)

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Finish Time: (24 hour time)

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Interviewer

Site Number:

(1=Opotiki/Te Kaha, 2=Whakatane, 3=Rotorua Māori, 4= Rotorua non-Māori, 5=NMO PHO, 6=WBOP PHO)

Place of Interview:

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1 = Residence 2 = Health Centre 3 = Other.....

Type of Interview:

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1 = Face-to-face with interviewer 2 = Phone 3 = Self completion

LILACS NZ participant's name

LILACS NZ participant's ID number

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CARER'S DETAILS

Carer's name:

I would like to check some of the details you have previously given us

CRA1. Do you still live at... (refer sheet for previous address)

No = 0 (Record new address) Yes = 1 (Go to CRA2)

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Full Address

.....

..... Phone

CRA2. New Carer

No = 0 (Go to CR5) Yes = 1

CR1. Caregiver status

1 = Informal caregiver/Family/friend 2 = Paid caregiver

CR2. Gender

1 = Male

2 = Female

CR3. Your date of birth

Date: . .
(dd) (mm) (yyyy)

CR3a. Your Age

Years

CR4. Which ethnic group(s) do you belong to?

(read all options and mark answers with No=0 Yes=1)

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

Other European

Other, such as Japanese, Tokelauan (state/ tuhituhi)

CR6. What is your relationship to the person you care for [i.e. the LILACS NZ Participant]?

Spouse / Partner	Sibling	Daughter or Son	Daughter-in-law or Son-in-law	Other family	Friend/ Neighbour	Grandchild	
1	2	3	4	5	6	7	<input type="checkbox"/>

CR5. In general would you say your health is:

Very good	Good	Fair	Poor	Very poor	
1	2	3	4	5	<input type="checkbox"/>

CR7. Your occupational status:

Employed full-time	Employed part-time	Retired	Not in paid employment	Full-time student	
1	2	3	4	5	<input type="checkbox"/>

CR7a. Are you receiving ...?

Carer's benefit	Other benefit	Other support (Specify)	No benefit	
1	2	3	0	<input type="checkbox"/>

.....
.....

CR8. Where do you live in proximity to [LiLACS NZ participant]?

- 1 = In the same household as [name of the Participant]
- 2 = In different household but the same property as [name of the Participant]
- 3 = Within walking distance of [name of the Participant]
- 4 = Within 10 minutes' drive/bus journey
- 5 = Between 10 and 30 minutes' drive/bus journey
- 6 = Within 1 hour drive/bus, plane journey
- 7 = Over 1 hour drive/bus, plane journey.
- 8 = In South Island
- 9 = Overseas

CR9. How often have you done each of the following for [LiLACS NZ participant] in the past 3 months?

	Daily	Several times a week	Once a week	Several times a month	Once a month or less	Never
a) Personal care For example help with dressing & undressing, eating, taking medication, washing and using the toilet	1	2	3	4	5	6
b) Household assistance For example help with shopping, transport, laundry, preparing meals, household chores, gardening and home maintenance	1	2	3	4	5	6

If CR9b is answered '6' skip to CR9c

CR9b-1. How often are you involved in the following?

	Daily	Several times a week	Once a week	Several times a month	Once a month or less	Never
1. Food choices	1	2	3	4	5	6
2. Food shopping	1	2	3	4	5	6
3. Food preparation	1	2	3	4	5	6
4. Cooking of meals	1	2	3	4	5	6
5. Preparing drinks and snacks	1	2	3	4	5	6
6. Sharing in the eating of meals	1	2	3	4	5	6

CR9. How often have you done each of the following for [*LiLACS NZ participant*] in the past 3 months?

	Daily	Several times a week	Once a week	Several times a month	Once a month or less	Never
c) Administrative/Legal Support For example help with arranging assistance from agencies, completing forms and document (eg taxes), WINZ, managing money, giving them money	1	2	3	4	5	6
d) Social and Emotional Support For example, checking on the person by phone, visiting, taking them out, read to, write letters, play cards with, etc.	1	2	3	4	5	6
e) Cultural Support (such as the arts) For example taking to, art galleries, ballet or theatre	1	2	3	4	5	6
j) Maori cultural activities	1	2	3	4	5	6
f) Spiritual Support For example praying with the older person, saying a prayer for the person, taking the person to church/a sacred place, being with the person	1	2	3	4	5	6
g) Family Support For example family celebrations, family picnics, managing family issues	1	2	3	4	5	6
h) Transport to health services For example taking them to the doctor, hospital or other health professional for treatment or advice	1	2	3	4	5	6
i) Other Please indicate any aspect of help or care not covered above	1	2	3	4	5	6

CR10. How long ago did you begin caring for [*LiLACS NZ participant*] in any of the ways you indicated in the last question?

Within the past 12 months (Go to CR11)	1-2 years ago (Go to CR11)	More than two years ago (Go to CR10a)
1	2	3

CR10a. If you began more than 2 years ago, when did you start?

Year

CR11. What is the total amount of time you spend giving such care in a typical week?

3 or less hours a week	4–9 hours a week	10–19 hours a week	20–49 hours a week	50+ hours a week	
1	2	3	4	5	<input type="text"/>

CR12. How much responsibility do you feel you have in relation to [LiLACS NZ participant]'s care?

All responsibility	Most of the responsibility	About half responsibility	Less than half	Hardly any responsibility	
1	2	3	4	5	<input type="text"/>

CR13. Have there been occasions during the past 3 months when you provided help in a crisis (e.g. an illness, accident, or family crisis) to [LiLACS NZ participant]?

No (Go to CR14)	Yes (Go to CR13a)	
0	1	<input type="text"/>

CR13a. If yes, about how many crises did you help out with within the past 3 months?

Crises

CR14. In the past 3 months, have you done any of the following for [LiLACS NZ participant]?

	No	Yes	
a. Sought information about community services for seniors	0	1	<input type="text"/>
b. Discussed care arrangements with other family members	0	1	<input type="text"/>
c. Made sure that their affairs were in order	0	1	<input type="text"/>
d. Taken steps to prepare for future change by:			
i. thought about moving closer together	0	1	<input type="text"/>
ii. Considered being more available for care and support needs	0	1	<input type="text"/>

CR15. How often do others (including spouse /children) help [LiLACS NZ participant]?

5	Never	Rarely	Sometimes	Often	Very often	
	1	2	3	4	5	<input type="text"/>

*Question CR16 is only for those who are employed (full time or part time). Refer to CR7
Others → Go to CR20*

CR16. In the last 3 months, please indicate if you used any of the following methods to provide help and support to [LiLACS NZ participant] .

	Never	Once	More than once	
a. Taken leave without pay	1	2	3	
b. Taken annual leave	1	2	3	
c. Used your own sick leave	1	2	3	
d. Taken "domestic" leave	1	2	3	
e. Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	1	2	3	
f. Paid someone else to provide care which you would have preferred to provide yourself	1	2	3	
g. Arranged with another family member to provide the care you normally provide	1	2	3	
h. Made phone calls or provided care yourself in work time	1	2	3	

CR20. What funded/subsidised government/community services do you know of that are available for older people in your area? (DO NOT PROMPT for answers)

No=0; Yes=1

Buses/taxis	<input type="checkbox"/>	Meal support	<input type="checkbox"/>
Home help (cleaning)	<input type="checkbox"/>	Age Concern	<input type="checkbox"/>
Home Help (shopping)	<input type="checkbox"/>	Stroke Foundation	<input type="checkbox"/>
Home Help (gardening)	<input type="checkbox"/>	Foundation of the Blind	<input type="checkbox"/>
Home Help (lawn mowing)	<input type="checkbox"/>	Alzheimer's Association	<input type="checkbox"/>
Personal Care (bathing/dressing etc.)	<input type="checkbox"/>	Other	<input type="checkbox"/>
Other	<input type="checkbox"/>	Other	<input type="checkbox"/>

CR21. Where do you get information about these services? (DO NOT PROMPT for answers)

No=0; Yes=1

General Practitioner	<input type="checkbox"/>	Medical Practice	<input type="checkbox"/>
Friends	<input type="checkbox"/>	Family	<input type="checkbox"/>
Paid caregiver or home help	<input type="checkbox"/>	The internet	<input type="checkbox"/>
Other (specify)		<input type="checkbox"/>	

CR22. How well informed are you about the general needs of [LiLACS NZ participant] ?

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	<input type="checkbox"/>

CR23. How well informed are you about the healthcare needs of [LiLACS NZ participant] ?

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	<input type="checkbox"/>

CR24. How well informed are you about and what is available to assist [LiLACS NZ participant] ?

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	<input type="checkbox"/>

CR25. How confident are you about accessing services to assist [LiLACS NZ participant] ?

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	<input type="checkbox"/>

COPE INDEX (CI1–15)

Thank you for answering the questions about your role as a carer to [LiLACS NZ participant]. Now, I would like to ask you how much support you feel you receive in your role as the carer.

CI1. Overall, do you feel well supported?

2	Always	Often	Sometimes	Never	
	1	2	3	4	<input type="checkbox"/>

CI2. Do you feel well supported by your friends and/or neighbours?

Always	Often	Sometimes	Never	N/A	
1	2	3	4	999	<input type="checkbox"/>

CI3. Do you feel well supported by your family?

Always	Often	Sometimes	Never	N/A	
1	2	3	4	999	<input type="checkbox"/>

CI4. Do you feel well supported by health and social services? (for example public, private, voluntary)

Always	Often	Sometimes	Never	N/A	
1	2	3	4	999	<input type="checkbox"/>

CI-A. How many people support you in your role as the carer?

(Count them up in discussion with the respondent, add up the various supporters)

Person sharing the care and support role	Number of people
i. Support regularly	
ii. Offers support occasionally	
iii. Will support if asked	
iv. Under special circumstances, planned in advance	
v. In a crisis	

CI5. Do you feel you cope well?

Always 1	Often 2	Sometimes 3	Never 4	
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2

CI6. Do you find caring worthwhile?

Always 1	Often 2	Sometimes 3	Never 4	
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CI7. Do you find caring too demanding?

Always 1	Often 2	Sometimes 3	Never 4	
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CI8. Do you have a good relationship with the person you care for?

Always 1	Often 2	Sometimes 3	Never 4	
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CI9. Does caring cause difficulties in your relationships with friends?

Always 1	Often 2	Sometimes 3	Never 4	N/A 999	
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CI10. Does caring cause difficulties in your relationships with your family?

Always 1	Often 2	Sometimes 3	Never 4	N/A 999	
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CI11. Do you feel that anyone appreciates you as a carer?

Always 1	Often 2	Sometimes 3	Never 4	N/A 999	
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CI12. Does caring have a negative effect on your physical health?

Always 1	Often 2	Sometimes 3	Never 4	
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CI13. Does caring have a negative effect on your emotional well-being?

Always 1	Often 2	Sometimes 3	Never 4	
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CI14. Does caring cause you financial difficulties?

Always 1	Often 2	Sometimes 3	Never 4	
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CI15. Do you feel trapped in your role as a carer?

Always 1	Often 2	Sometimes 3	Never 4	
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Now, think about your role as the carer

CR17. On the whole, how important is your love and support to the wellbeing of the person you care for?

Not at all	A little/	Moderately	A lot	Very important	
1	2	3	4	5	<input type="checkbox"/>

CR18. Is there anything else you would like to say about your role as a carer?

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.....

The questions in the last section are about you

EQ-5D-3L HEALTH QUESTIONNAIRE

For each category, please indicate the ONE statement that best describes your own health state TODAY

EEQ1. MOBILITY

I have no problems in walking about	I have some problems in walking about	I am confined to bed	
0	1	2	<input type="checkbox"/>

EEQ2. SELF CARE

I have no problems with self-care	I have some problems washing or dressing myself	I am unable to wash or dress myself	
0	1	2	<input type="checkbox"/>

EEQ3. USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities	I have some problems with performing my usual activities	I am unable to perform my usual activities	
0	1	2	<input type="checkbox"/>

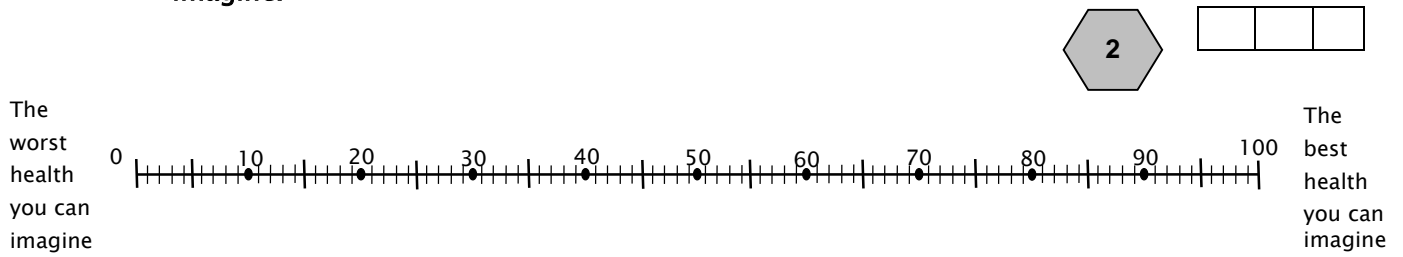
EEQ4. PAIN / DISCOMFORT

I have no pain or discomfort	I have moderate pain or discomfort	I have extreme pain or discomfort	
0	1	2	<input type="checkbox"/>

EEQ5. ANXIETY / DEPRESSION

I am not anxious or depressed	I am moderately anxious or depressed	I am extremely anxious or depressed	
0	1	2	<input type="checkbox"/>

AEQ6. We would like to know how good or bad your health is TODAY. Please score your health out of 100; 100 means the best health you can imagine, 0 means the worst health you can imagine.



THANK YOU for being part of the study

OTHER COMMENTS: