

To return questionnaire to
participant Yes No

QUESTIONNAIRE FOR INFORMAL CARER
E PATAITAI MO ETAHI ATU AHUA AROHA--KAI-AWHINA



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 3 ~

This questionnaire has been developed by the LILACS NZ research team and is for the purpose of the LILACS NZ project. Please contact Professor Ngaire Kerse at the LILACS NZ research base.
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QUESTIONNAIRE FOR INFORMAL CARER

Te wa/Date: . .
(dd) (mm) (yyyy)

Start Time: (24 hour time/ Wa Timata rua tekau ma wha haora)

Finish Time: (24 hour time/ Wa mutu rua tekau ma wha haora)

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Interviewer

Place of Interview:

1 = Residence

2 = Health Centre

3 = Other.....

Nga whakamohiotanga ahua o te Kaiawhina CARER'S DETAILS

CR1. Nga tuunga o te Kaiawhina / Caregiver status

1 = whanau/hoa/Arohakaiawhina
Informal carer /Family/friend

2 = Utua Kaiawhina
Paid caregiver

CR2. Ira Tangata / Gender

1 = Tane/Male

2 = Wahine/Female

CR3. To ra whanau / Your date of birth

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

CR4. Ko ehea ou iwi i heke mai koe / Which ethnic group(s) do you belong to?

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

New Zealand European
Cook Island Māori
Chinese

Māori
Tongan
Indian

Samoan
Niuean
Other European

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

CR5. Ka korero koe e pehea ana tou hauora / Would you say your health is:

Tino pai Very good	E paiana Good	Kei te pai Fair	Kahore it e pai Poor	Kei te taumaha Very poor
1	2	3	4	5
				<input type="text"/>

CR6. He aha tou whanautanga ki te tangata e kaiwhinatia na e koe, [ara te LILACS NZ Kaumatua]?

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

Hoa rangatira /Hoa moe Spouse / Partner	Tuakana-teina Sibling	Tamahine /Tama Daughter or Son	Tamahine hungaona/ Tama hungaona Daughter-in-law or Son-in-law	E ra atu whanau Other family	Hoa/ Hoa noho tata Friend/ Neighbour	Mokopuna Grandchild	
1	2	3	4	5	6	7	<input type="checkbox"/>

CR7. To ahua mahi / Your occupational status:

Ae kai te mahi ia tau ia tau Employed full-time <i>Go to CR8</i>	Ae kai te mahi ia wa ia wa Employed part-time <i>Go to CR8</i>	Ae kua mutu te mahi Retired <i>Go to CR8</i>	Kahore i te whiwhi mahi Not in paid employment	He akonga ia tau ia tau Full-time student <i>Go to CR8</i>	
1	2	3	4	5	<input type="checkbox"/>

CR7. Are you receiving?

1 = Carer's benefit

2 = Other benefit

3 = Other support (specify)

.....

CR8. Pehea to noho tata atu kite [Kaumatua]?

Where do you live in proximity to [name of the Participant]?

- 1 = I roto i te whare e noho ana te {Kaumatua}?
In the same household as [name of the Participant]
- 2 = Ae i roto ano i oku ruma, engari ko te whare e noho ana te [Kaumatua]ra.
In a different household but the same property as [name of the Participant]
- 3 = Tata noiho pai noiho te hikoi atu
Within walking distance of [name of the Participant]
- 4 = Ae i roto i te tekau miniti noihi ma te motoka, pahi ranei.
Within 10 minutes' drive/bus journey
- 5 = Ae i roto i te toru tekau miniti, ma te motoka, pahi ranei.
Within 30 minutes' drive/bus journey
- 6 = Ae i roto i te tahi haora taraiwa/pahi, waka rere rangi ranei.
Within 1 hour drive/bus, plane journey
- 7 = Ko atu i te haora, taraiwa, pahi, waka rere rangi ranei
Over 1 hour drive/bus, plane journey.
- 8 = Mai i Te Wai Pounamu
In South Island
- 9 = Mai i Tawahi
Overseas

CR9. How often have you done each of the following for [name of the Participant] in the past 3 months?

	Daily	Several times a week	Once a week	Several times a month	Once a month or less	Never	
<p>a) Personal care</p> <p>Kiko manaaki; ara ko te whaka uru ki onga kakahu, a ki te tango hoki i ona kakahu, ki te whangai, ki te whaka inu i ona rongoa, ki te horoi i a ia, ki te awhina i a ia i te whare paku.</p> <p>For example help with dressing & undressing, eating, taking medication, washing and using the toilet</p>	1	2	3	4	5	6	
<p>b) Household assistance</p> <p>Whare noho awhina; ara ko te haere ki te hoko hoko mai, i nga toa, mahi i nga mara kai, a ki te whaka tika tika i te kainga]</p> <p>For example help with shopping, transport, laundry, preparing meals, household chores, gardening and home maintenance</p>	1	2	3	4	5	6	
<p>c) Administrative/Legal Support</p> <p>Ara ko te awhina i a ia ki te haere ki nga tautoko awhina, mai i nga ropu awhina kawangatanga, ki te tika te whaka ki haere i nga pepa, mai i te tari take, mai ia WINZ, kia tika hoki tanga tiaki i ana putea, a ki to houatu hoki e putea awhina.</p> <p>For example help with arranging assistance from agencies, completing forms and document (eg taxes), WINZ, managing money, giving them money</p>	1	2	3	4	5	6	
<p>d) Social and Emotional Support</p> <p>Tikanga awhina me te tikanga aroha awhina; ara mo te pataitai i runga i te waea kai te pehea ratou, haere anga ki te matakitaki, kawea a nga ki te haereere, ki te riiti pukapuka kia ratou, ki te purei kaari, me etahi atu mahi hoa hoa.</p> <p>For example, checking on the person by phone, visiting, taking them out, read to, write letters, play cards with, etc.</p>	1	2	3	4	5	6	
<p>e) Tikanga Awhina / Cultural Support</p> <p>ki te kawe ki nga tangihana, ki te maataki i nga mokopuna.</p> <p>For example taking to Tangihana, art galleries, ballet or theatre</p>	1	2	3	4	5	6	
<p>f) He tikanga awhina: / Spiritual Support</p> <p>Ara me karakia i te taha o te koroheke, e tuku karakia ana mo toua tangata, kawea ana toua tangata ki te whare karakia, te tahi wahi atu tuku karakia. hei hoa noiho.</p> <p>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</p>	1	2	3	4	5	6	

	Daily	Several times a week	Once a week	Several times a month	Once a month or less	Never	
g) Whanau awhina / Family Support Ara na whanau hui whakanui, na haereere ki nga whanau pikiniki, whaka haere ana i nga take whanau For example family celebrations, family picnics, managing family issues	1	2	3	4	5	6	
h) E waka hei haere ki nga tari Hauora / Transport to health services Ara hei ia ratou ki te takuta, ki te hohipera, ki etahi atu tohunga hauora tirotiro, mo te whakaora mate, mo te homai korero whakaora. For example taking them to the doctor, hospital or other health professional for treatment or advice	1	2	3	4	5	6	
i) Other Etahi atu; Aku inoi nui ki a koe, mehemea e take, e aha ranei, i mahue atu i waho, kahore i roto enei whaka rite. Please indicate any aspect of help or care not covered above	1	2	3	4	5	6	

CR10. E hia te roa atu i timata to awhina i te [Kaumatua]i nga ahuatanga i tohuria mai e koe i roto i nga pataitai, i tata muri atu nei.

How long ago did you begin caring [*name of the Participant*] in any of the ways you indicated in the last question?

I roto i nga tekaumarua marama kua taka Within the past 12 months (Go to CR11)	Tahi ki te rua tau kua taka atu 1-2 years ago (Go to CR11)	Ko atu i te rua tau More than two years ago (Go to CR10a)	
1	2	3	

CR10a. Mehemea i timata mai koe, ko atu i te rua tau, no nahea koe i timata ai?

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

Nga Tau/ Year

CR11. E hia o te wa katoa ka tukua e koe ki te mahi awhina o ia wiki mahi penei ai?

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

E toko toru heke atu haora ia wiki 3 or less hours a week	Tokowha ki te tokoiwa haora ia wiki 4-9 hours a week	Tekau ki te tekau ma iwa haora ia wiki 10-19 hours a week	E rua tekau ki te wha tekau ma iwa haora 20-49 hours a week	E rima tekau haora ia wiki 50+ hours a week	
1	2	3	4	5	

CR12. Ki a koe e hia ou manawhakahaere awhina i te [Kaumatua] nei.

How much responsibility do you feel you have in relation to [name of the Participant] care?

Te katoa All responsibility	Te nuinga o te awhina Most of the responsibility	Tata ki te haawhe te awhina About half responsibility	Heke atu i te haawhe less than half	Hardly any responsibility Paku iti noiho te awhina Hardly any responsibility	
1	2	3	4	5	<input type="checkbox"/>

CR13. E wa ano i roto i nga toko toru marama kua taka, i awhinatia e koe i nga wa morearea (pera i te mauui, i te aitua, a e whanau raruraru, ki te [Kaumatua])?

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 [name of the Participant]?

Kao/No (Go to CR14)	Haere ki/Yes (Go to CR13a)	
0	1	<input type="checkbox"/>

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

Crises

CR14. I roto i nga toko toru marama kua taka, kua mahi ano koe i enei mea e whai ake nei mo te [Kaumatua]?

In the past 3 months, have you done any of the following for [name of the Participant]?

	Kao/No	Ae/Yes	
a. Rapu whakaatu korero awhina mo etahi hapori umanga mo nga kaumatua? Sought information about community services for seniors	0	1	<input type="checkbox"/>
b. Whakawhiti whakaaro mo te manaaki ki te whanau Discussed care arrangements with other family members	0	1	<input type="checkbox"/>
c. Kia tino mohio kei te pai te takoto o ana meatanga. Made sure that their affairs were in order	0	1	<input type="checkbox"/>
d. I whakaritea ki te whakatikatika mo etahi ahua e heke mai ana. Taken steps to prepare for future change by:			<input type="checkbox"/>
i. I whakaarotia kia noho tata mai / thought about moving closer together	0	1	<input type="checkbox"/>
ii. I whakaarotia kia maha atu te wa mo te aawhina me nga tautoko hiahia. Considered being more available for care and support needs	0	1	<input type="checkbox"/>

CR15. E hia te wa, a etahi atu, nga hoa, nga tamariki, e kaiawhina ana?

How often do others (including spouse /children) help [name of the Participant]?

Kore Never	Tino iti Rarely	Ia wa Sometimes	Etahi wa Often	Wa iti Very often	
1	2	3	4	5	<input type="checkbox"/>

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

CR16. I roto i nga marama e toru kua taka, korerotia mai mehemea i mahia e koe enei huawhakatutuki kaupapa hei awhina i te Kaumatua.

In the last 3 months, please indicate if you used any of the following methods to provide help and support to [name of the Participant].

	Kore Never	Kotahi Once	Wa iti More than once	
a. I whakatau mai i to mahi mo te kore utu. Taken leave without pay	1	2	3	<input type="checkbox"/>
b. Whakatau hararei a tau. Taken annual leave	1	2	3	<input type="checkbox"/>
c. Whakatau ou ano hararei mauui Used your own sick leave	1	2	3	<input type="checkbox"/>
d. Whakatau ou kainga hararei Taken "domestic" leave	1	2	3	<input type="checkbox"/>
e. I whakatau ano, e waa whaka-kapi, e wa whakaneke, i whaka-ritea koe me too Rangatira, me o hoa mahi Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	1	2	3	<input type="checkbox"/>
f. I utua te tahi atu hei kaiawhina engari ki tou hiahia mau tonu e tiaki Paid someone else to provide care which you would have preferred to provide yourself	1	2	3	<input type="checkbox"/>
g. Ngau i whakarite ma te tahi ano o tou whanau e manaaki ou ano mahi Arranged with another family member to provide the care you normally provide	1	2	3	<input type="checkbox"/>
h. I waea e koe a i kaiawhinga koe i roto i o wa mahi Made phone calls or provided care yourself in work time	1	2	3	<input type="checkbox"/>

COPE INDEX (CI1-15)

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

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CI1. Overall, do you feel well supported?

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	

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CI5. Do you feel you cope well?

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

CI6. Do you find caring worthwhile?

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

CI7. Do you find caring too demanding?

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

CI8. Do you have a good relationship with the person you care for?

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

CI9. Does caring cause difficulties in your relationships with friends?

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

CI10. Does caring cause difficulties in your relationships with your family?

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

CI11. Do you feel that anyone appreciates you as a carer?

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

CI12. Does caring have a negative effect on your physical health?

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

CI13. Does caring have a negative effect on your emotional well-being?

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

CI14. Does caring cause you financial difficulties?

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

CI15. Do you feel trapped in your role as a carer?

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

Now, think about your role as the carer

CR17. Mo te katoa or to awhina i te kaumatua [ingoa] nei, i ou whakaaro e pehea ana tou awhina mo tona hauora? / On the whole, how important is your love and support to the wellbeing of the person you care for?

Kahore Not at all	E iti nei A little/	la wa ano Moderately	E wa roa tonu A lot	E nui rawaatu 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?

.....
.....
.....

CR19. During their interview, [name of participant] answered some questions about their hopes and wishes at the end of their life. Would you be willing to be contacted following their death to talk about how closely their wishes were met?

No	Yes	
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0	1	
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THANK YOU for being part of the study

COMMENTS