

ID# \_\_\_\_\_

**CAREGIVER QUESTIONNAIRE**  
**Registration Information** *This page is to be kept at Study Centre*

**STUDY SUBJECT** *Complete using CSHA-3 Subject Information Sheet and information from coordinator*

**Name:** \_\_\_\_\_  
Surname (Maiden Name) Given Names

**CSHA-3 Address:** \_\_\_\_\_  
No. Street (Apt #)  
\_\_\_\_\_ Town/City Province Postal Code

**Sex:** 1 Male 2 Female **D.O.B.:** \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
DD MM YYYY

**CAREGIVER** *Complete at time of phone call if you have not already confirmed this information*

**Name:** \_\_\_\_\_  
Surname (Maiden Name) Given Names

**CSHA-3 Address:** \_\_\_\_\_  
No. Street (Apt #)  
\_\_\_\_\_ Town/City Province Postal Code

**Are you involved in caring for ( )?**

1 Yes

2 No

**Does ( ) need care?**

1 Yes

2 No

**Would you provide care if this was needed?**

2 No

1 Yes

**Are you the main caregiver?**

1 Yes

2 No

**Who is the main person who helps (or would help) with care?**

Please specify: \_\_\_\_\_

ID# \_\_\_\_\_

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English 3

<b>Part of Clinical</b>	<b>1</b>
<b>Frail sample</b>	<b>2</b>


# CANADIAN STUDY OF HEALTH AND AGING-3

## CAREGIVER QUESTIONNAIRE

Office use only:

- Complete
- Incomplete
- Edited

Health Consent signed?  Yes  No

 Time interview started: \_\_\_\_ : \_\_\_\_  
(24-hour clock)

Date of interview: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
                                  dd   mm   yyyy

Editor # \_\_\_\_\_

Interviewer # \_\_\_\_\_

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**Canadian Study of Health & Aging - 3**  
**CAREGIVER QUESTIONNAIRE**  
**Identifying Information**

*Complete before the interview*

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**STUDY SUBJECT** *Complete using CSHA-3 Subject Information Sheet*

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A.1 **Sex:**                    1 Male            2 Female

A.2 **D.O.B.:**                       /        /         
  DD    MM   YYYY

A.3 **Date of CSHA-3 Screening Interview:**                       /        /         
  DD    MM   YYYY

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**CAREGIVER** *Complete before the interview*

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A.5 **Caregiver sex:**            1 Male            2 Female

A.6 **Care needed?:**            1 Yes            2 No

A.7 **Main caregiver or would be if needed?**    1 Yes    2 No

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Task (In last month)	Has anyone helped (____) with the task during the last month?	Relationship to (____)?	How many times do you/they help per month?
<b>c. Can (____) take care of his/her own appearance, for example, combing his/her hair and (for men shaving) ...</b>  2 without any help  1 with some help  0 or is he/she completely unable to do this?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	7 R      77 R	2	
	8 DK      88 DK		
<b>d. Can (____) walk ...</b>  2 without any help (except a cane)  1 with some help (from a person, or using a walker, crutches or chair)  0 or is he/she completely unable to walk?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	3 Device only      77 R	2	
	7 R      88 DK		
<b>e. Can (____) get in and out of bed ...</b>  2 without any help  1 with some help (person or device)  0 or is he/she completely unable to get in and out of bed unless someone lifts him/her?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	3 Device only      77 R	2	
	7 R      88 DK		
	8 DK	3	

Task (In last month)	Has anyone helped (____) with the task during the last month?	Relationship to (____)?	How many times do you/they help per month?
<b>f. Can (____) take a bath or shower ...</b>  2 without any help  1 with some help (person or device)  0 or is he/she completely unable to bathe?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	3 Device only      77 R	2	
	7 R      88 DK		
	8 DK	3	
<b>g. Can (____) go to bathroom or toilet ...</b>  2 without any help  1 with some help (person or device)  0 or is he/she completely unable to use the bathroom or commode unless someone moves him/her?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	3 Device only      77 R	2	
	7 R      88 DK		
	8 DK	3	
<b>h. Can (____) use the telephone ...</b>  2 without any help (look up numbers and dial)  1 with some help (can answer phone, dial operator in an emergency, but needs special phone or help in getting numbers or dialing)  0 or is he/she completely unable to use the phone?  7 R      8 DK	1 Yes → <b>How many?</b>	1	
	2 No      _____		
	3 Device only      77 R	2	
	7 R      88 DK		
	8 DK	3	

Task (In last month)	Has anyone helped (____) with the task during the last month?	Relationship to (____)?	How many times do you/they help per month?
<b>i. Can (____) get to places out of walking distance ...</b>	1 Yes → <b>How many?</b>	1	
	2 No _____		
	3 Device only 77 R	2	
	7 R 88 DK		
1 with some help (needs someone to help or go with him/her when travelling)	8 DK		
0 or is he/she completely unable to travel unless special arrangements are made?		3	
7 R 8 DK			
<b>j. Can (____) go shopping for his/her groceries or clothes (assuming they have transportation) ...</b>	1 Yes → <b>How many?</b>	1	
	2 No _____		
	7 R 77 R	2	
	8 DK 88 DK		
1 with some help (needs someone to go with him/her on all shopping trips)		3	
0 or is he/she completely unable to do any shopping?			
7 R 8 DK			
<b>k. Can (____) prepare his/her own meals ...</b>	1 Yes → <b>How many?</b>	1	
	2 No _____		
	7 R 77 R	2	
	8 DK 88 DK		
1 with some help (can do some things but not prepare full meals)		3	
0 or is he/she completely unable to prepare any meals?			
7 R 8 DK			



Task (In last month)	Has anyone helped (____) with the task during the last month?	Relationship to (____)?	How many times do you/they help per month?
<b>l. Can (____) do his/her housework ...</b> 2 without any help (scrubs floors, etc.) 1 with some help (can do light work but not heavy work) 0 or is he/she completely unable to do housework? 7 R    8 DK	1 Yes → <b>How many?</b>	1	
	2 No    _____	2	
	7 R    77 R 8 DK    88 DK	3	
<b>m. Can (____) take his/her own medicine ...</b> 2 without any help (in the right dose at the right time) 1 with some help (can take medication if someone prepares it and reminds him/her to take it) 0 or is he/she completely unable to take his/her own medicine? 7 R    8 DK	1 Yes → <b>How many?</b>	1	
	2 No    _____	2	
	7 R    77 R 8 DK    88 DK	3	
<b>n. Can (____) handle his/her own money ...</b> 2 without any help 1 with some help (can manage day-to-day buying but needs help with cheque book and paying bills) 0 or is he/she completely unable to handle money? 7 R    8 DK	1 Yes → <b>How many?</b>	1	
	2 No    _____	2	
	7 R    77 R 8 DK    88 DK	3	

**CARE MANAGEMENT**

**7. How often, on average, do you...  (SHOW CARD #2)**

- |   |                     |   |                     |
|---|---------------------|---|---------------------|
| 1 | Never               | 5 | Several times/month |
| 2 | Less than once/year | 6 | Once/week           |
| 3 | Several times/year  | 7 | Several times/week  |
| 4 | Once/month          | 8 | Daily               |

**a) ... schedule Home Care or other support workers for (\_\_\_\_\_)**

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|

**b) ... make appointments for (\_\_\_\_\_)**

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|

**c) ... check to see how (\_\_\_\_\_) is doing, either in person or by telephone**

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|

**d) Is there anything else you do to manage care for (\_\_\_\_\_)?**  
(Record verbatim and indicate frequency)

- |       |   |   |   |   |   |   |   |   |
|-------|---|---|---|---|---|---|---|---|
| _____ | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|-------|---|---|---|---|---|---|---|---|

- |       |   |   |   |   |   |   |   |   |
|-------|---|---|---|---|---|---|---|---|
| _____ | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|-------|---|---|---|---|---|---|---|---|

- |       |   |   |   |   |   |   |   |   |
|-------|---|---|---|---|---|---|---|---|
| _____ | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|-------|---|---|---|---|---|---|---|---|

If no ADL or IADL problems, Go to Q. 9

**8. How long ago did you first have to start helping (him/her) do things that (he/she) was no longer able to do?**

- |   |                             |    |                          |
|---|-----------------------------|----|--------------------------|
| 1 | Less than 6 months ago      | 5  | 6-10 years ago           |
| 2 | Between 6 and 12 months ago | 6  | 11 or more years ago     |
| 3 | 1-2 years ago               | 7  | R                        |
| 4 | 3-5 years ago               | 8  | DK                       |
|   |                             | 66 | NA (Needs no assistance) |

**9. Who would take over your role of caring for (\_\_\_\_\_) if you were not available?**  
(Code relationship to care recipient)

- |    |                 |    |                 |    |                        |
|----|-----------------|----|-----------------|----|------------------------|
| 1  | Wife            | 11 | Brother-in-law  | 23 | Great granddaughter    |
| 2  | Husband         | 12 | Paid caregiver  | 24 | Great grandson         |
| 3  | Daughter        | 13 | Volunteer       | 25 | Niece's daughter       |
| 4  | Son             | 16 | Nephew          | 26 | Niece's son            |
| 5  | Sister          | 17 | Niece           | 29 | Institution's Staff    |
| 6  | Brother         | 18 | Grandson        | 30 | Family unspecified     |
| 7  | Friend          | 19 | Granddaughter   | 77 | R                      |
| 8  | Daughter-in-law | 20 | Nephew's wife   | 88 | DK                     |
| 9  | Son-in-law      | 21 | Niece's husband | 90 | Other <i>specify</i> : |
| 10 | Sister-in-law   | 22 | Cousin          |    | _____                  |

**THE CAMDEX**

The following questions relate to changes in (\_\_\_\_\_)’s awareness, behaviour and character during the past five years. These changes do not always appear in late life, and may not be relevant to him/her, but we have to ask these of everybody in order to be consistent.

Note: 6=NA 7=R 8=DK

**10. Personality**

In the past five years:

- 238. Have you noticed any changes in his/her personality, such as the way he/she behaves socially?**
- |           |   |  |   |
|-----------|---|--|---|
| No .....  | 2 |  | 7 |
| Yes ..... | 1 |  | 8 |

Specify type of change: \_\_\_\_\_

- 239. Has there been any noticeable exaggeration in his/her normal character?**
- |           |   |  |   |
|-----------|---|--|---|
| No .....  | 2 |  | 7 |
| Yes ..... | 1 |  | 8 |

- 240. Has he/she become more (or less) changeable in mood?**
- |           |   |  |   |
|-----------|---|--|---|
| No ..     | 2 |  | 7 |
| Yes. .... | 1 |  | 8 |

- 241. Has he/she become more (or less) irritable or angry?**
- |       |   |  |   |
|-------|---|--|---|
| No .  | 2 |  | 7 |
| Yes . | 1 |  | 8 |

- PFQ1. Has he/she become more aggressive?**
- |       |   |  |   |
|-------|---|--|---|
| No .  | 2 |  | 7 |
| Yes . | 1 |  | 8 |

- 244. Has he/she become more stubborn or perhaps a little awkward? Or less?**
- |            |   |  |   |
|------------|---|--|---|
| No .....   | 2 |  | 7 |
| Less ..... | 1 |  | 8 |
| More ..... | 0 |  |   |

**11. Memory**

- 247. Does he/she have difficulty remembering short lists of items, e.g. a shopping list?**
- |                         |   |  |   |
|-------------------------|---|--|---|
| No difficulty .....     | 2 |  | 7 |
| Slight difficulty ..... | 1 |  | 8 |
| Great difficulty .....  | 0 |  |   |

- 247a. If difficulty, How long has this difficulty been present?**
- |                          |     |  |  |
|--------------------------|-----|--|--|
| Duration in months _____ |     |  |  |
| NA .....                 | 666 |  |  |
| R .....                  | 777 |  |  |
| DK .....                 | 888 |  |  |

<b>248.</b>	<b>Does he/she have difficulty remembering recent events (e.g., when he/she last saw you, or what happened the day before?)</b>	No difficulty . . . . . 2 Slight difficulty . . . . . 1 Great difficulty . . . . . 0	7 8 0
<b>248a.</b>	<b><u>If difficulty</u>, How long has this difficulty been present?</b>	Duration in months _____ NA . . . . . 666 R . . . . . 777 DK . . . . . 888	
<b>249.</b>	<b>Does he/she have difficulty interpreting surroundings (e.g. knowing where he/she is, or discriminating between different types of people, such as doctors, visitors, relatives?)</b>	No difficulty . . . . . 2 Slight difficulty . . . . . 1 Great difficulty . . . . . 0	7 8 0
<b>250.</b>	<b>Does he/she have difficulty finding the way about home (or ward), e.g. finding the toilet?</b>	No difficulty . . . . . 2 Slight difficulty . . . . . 1 Great difficulty . . . . . 0	7 8 0
<b>251.</b>	<b>Does he/she have difficulty finding the way around the neighbourhood, e.g. to the shops near home?</b>	No difficulty . . . . . 2 Slight difficulty . . . . . 1 Great difficulty . . . . . 0	7 8 0

If no memory problems in questions 247-251, omit questions 252, 252a, 253a & 253b and code 6 or 666 for each:

<b>252.</b>	<b>Have these changes developed gradually or did they come on suddenly?</b>	Gradually . . . . . 2 Suddenly . . . . . 1	6 7 8
<b>252a.</b>	<b>When did these changes first appear?</b>	_____ month    year NA . . . . . 666 R . . . . . 777 DK . . . . . 888	
<b>253a.</b>	<b>When did his/her memory problems first affect his/her social or family life?</b>	_____ month    year NA . . . . . 666 R . . . . . 777 DK . . . . . 888	
<b>253b.</b>	<b>Has he/she consulted a doctor about his/her memory problems?</b>		
	1 Yes            2 No		
	<b><u>If yes</u>, When was the first consultation?</b>	_____ month    year NA . . . . . 666 R . . . . . 777 DK . . . . . 888	

12. *General Mental Functioning*

254.	<b>Has there been a more general decline in his/her mental functioning? For example, is it less clear or sharp?</b>	No .....	2	7
		Yes .....	1	8
255.	<b>Does he/she tend to talk about what happened long ago rather than in the present?</b>	No .....	2	7
		Sometimes .....	1	8
		Often .....	0	
256.	<b>When speaking, does he/she have difficulty finding the right word, or use wrong words?</b>	No .....	2	7
		Yes .....	1	8
257.	<b>Does he/she seem to find it more difficult to make decisions lately?</b>	No .....	2	7
		Yes .....	1	8
258.	<b>Is there a loss of any special skill or hobby he/she could manage before?</b>	No .....	2	7
		Yes .....	1	8
259.	<b>Does his/her thinking seem muddled?</b>	No .....	2	7
		Yes .....	1	8
PFQ2.	<b>Does he/she have problems maintaining a train of thought?</b>	No .....	2	7
		Yes .....	1	8

13. *Paranoid Features*

PFQ3.	<b>Has he/she become more suspicious?</b>	No .....	2	7
		Yes .....	1	8
286.	<b>Has he/she complained unjustifiably of being persecuted or spied on by others?</b>	No .....	2	7
		Yes .....	1	8
	<b>286a. <u>If yes</u>, How long has this been present?</b>	Duration in months _____		
		NA .....	666	
		R .....	777	
		DK .....	888	
287.	<b>Has he/she been troubled by voices or visions not experienced by others?</b>	No .....	2	7
		Yes .....	1	8
	<b>287a. <u>If yes</u>, How long has this been present?</b>	Duration in months _____		
		NA .....	666	
		R .....	777	
		DK .....	888	

14. *Clouding/Delirium*

271.	<b>Are there periods lasting days or weeks when his/her thinking seems quite clear, but then becomes muddled?</b> If NO: Go to 275	No . . . . . 2 Yes . . . . . 1	6 7 8
If YES:			
272.	<b>Are there brief episodes during 24 hours when he/she seems worse, and then times when his/her thinking seems quite clear?</b>	No . . . . . 2 Yes . . . . . 1	6 7 8
273.	<b>Is the confusion worse towards dusk or in the evening?</b>	No . . . . . 2 Yes . . . . . 1	6 7 8
274.	<b>How long has this difficulty been present?</b>	Duration in months _____ NA . . . . . 666 R . . . . . 777 DK . . . . . 888	

15. *Depressed Mood*

275.	<b>Does he/she show a loss of interest or enjoyment in things in general?</b>	No . . . . . 2 Yes . . . . . 1	7 8
276.	<b>Do you think that he/she is depressed?</b>	No . . . . . 2 Yes . . . . . 1	7 8

16. *Sleep*

283.	<b>Does he/she tend to get up and wander at night or at any other time?</b>	No . . . . . 2 Yes . . . . . 1	7 8
SL1.	<b>On a scale of 1 to 5 rate his/her tendency to snore:</b>	Virtually never snores . . . . . 1 Occasionally snores softly . . . . . 2 Moderate snorer . . . . . 3 Quite severe snoring is usual . . . . . 4 Severe, frequent and bizarre snoring 5 R . . . . . 7 DK . . . . . 8	
SL2.	<b>Was he/she ever <u>diagnosed</u> as having obstructive sleep apnea?</b>	No . . . . . 2 Yes . . . . . 1	7 8

17. *Cerebrovascular Problems*

288. **Has he/she ever passed out and then had a brief weakness or difficulty with speech, memory or vision?** No ..... 2 7  
 Yes ..... 1 8
289. **Does he/she have a tendency to fall?** No ..... 2 7  
 Yes ..... 1 8
290. **Has he/she ever had a stroke?** No ..... 2 7  
 Yes ..... 1 8

If any answer to 288 - 290 is 'Yes', ask 291. If all answers are 'No', code 666 and 6, below.

291. **How long ago did this occur?** Months ago \_\_\_\_\_  
 NA ..... 666  
 R ..... 777  
 DK ..... 888
267. **Does he/she have problems with incontinence?** No ..... 3 6  
 Wets occasionally ..... 2 7  
 Wets often ..... 1 8  
 Doubly incontinent ..... 0

If no problem has been established anywhere in Questions 238-291, code 6 and 666 for questions 292-294.

292. **Does he/she have trouble getting about since the onset of the above difficulties?** No difficulty ..... 2 6  
 Slight difficulty ..... 1 7  
 Great difficulty ..... 0 8
293. **You have indicated some changes in ( \_\_\_\_ ). Can you tell me what was the first change noticed in his/her behaviour? (Record answer in full)**

- 293a. **How long ago was that?** Time ago in months \_\_\_\_\_  
 NA ..... 666  
 R ..... 777  
 DK ..... 888
294. **When, in your judgement, was his/her mental ability last quite normal?** Month / Year \_\_\_\_ / \_\_\_\_  
 NA ..... 666  
 R ..... 777  
 DK ..... 888

**18. CAMDEX Part II.** *Pertaining to the Subject's Past History*

I would now like to ask you about other aspects of (\_\_\_\_\_)’s health in the past.

- |             |   |  |             |
|-------------|---|--|-------------|
| <b>295.</b> | <b>Has he/she ever been told by a doctor that he/she had high blood pressure?</b> | No . . . . . 2<br>Yes . . . . . 1                              | 7<br>8      |
| <b>296.</b> | <b>Has he/she ever been told by a doctor that he/she had had a heart attack?</b>  | No . . . . . 2<br>One . . . . . 1<br>More than one . . . . . 0 | 7<br>8<br>8 |
| <b>297.</b> | <b>Has he/she ever been diagnosed as diabetic?</b>                                | No . . . . . 2<br>Yes . . . . . 1                              | 7<br>8      |
| <b>298.</b> | <b>Has he/she been diagnosed as having Parkinson's disease?</b>                   | No . . . . . 2<br>Yes . . . . . 1                              | 7<br>8      |
| <b>300.</b> | <b>Is he/she currently being treated for cancer?</b>                              | No . . . . . 2<br>Yes . . . . . 1                              | 7<br>8      |

**DR1.** In the past 5 years, has (\_\_\_\_) ever had a drug treatment for Alzheimer’s disease?

- 1 Yes      2 No      7 R      8 DK

If YES: **What did he/she take?** (Check all that apply)

- |                          |       |                   |       |
|--------------------------|-------|-------------------|-------|
| Aricept / Donepezil      | _____ | Ginko (Biloba)    | _____ |
| Exelon / Rivastigmine    | _____ | Vitamin E         | _____ |
| Other experimental drugs | _____ | Nonsteroidal      | _____ |
|                          |       | Anti-inflammatory | _____ |
- Other drugs (name them)
- \_\_\_\_\_

- |              |  |  |                  |
|--------------|--|--|------------------|
| <b>301.</b>  | <b>Has he/she ever been unconscious after a head injury?</b> | No . . . . . 2<br>1 injury . . . . . 1<br>2 injuries . . . . . 3<br>3 injuries or more . . . . . 4 | 7<br>8<br>8<br>8 |
| <b>301a.</b> | <b>If YES, At what age?</b><br>Specify age: _____            |  |                  |



<b>302.</b>	<b>Has he/she ever had seizures?</b>	No .....	2	7
	<b>302a.</b> If YES, specify age of onset: _____	Infantile only .....	1	8
		Past seizures only (non-infantile) .....	3	
		Current seizures .....	4	
<b>303.</b>	<b>Has he/she ever been a heavy smoker, say 20 or more cigarettes a day for a year or more?</b>	No .....	2	7
		Yes .....	1	8
<b>304.</b>	<b>Has he/she ever drunk alcohol such as beer, wine or spirits?</b>	No .....	2	7
	If NO: go to 307	Yes .....	1	8
	If YES, continue:			
	<b>305.</b> Did you ever think he/she was a heavy drinker?	No .....	2	7
		Yes .....	1	8
	<b>306.</b> Did drinking ever cause him/her any problems such as losing jobs, or with driving?	No .....	2	7
		Yes .....	1	8
<b>307.</b>	<b>Has he/she ever taken pills or drugs that he/she felt unable to manage without, for instance barbiturates to help him/her sleep, or purple hearts (amphetamines) to help him/her cope?</b>	No .....	2	7
		Tranquillizers .....	1	8
		Hypnotics .....	3	
		Barbiturates .....	4	
		Stimulants .....	5	
	Specify others: _____	Others .....	6	
<b>309.</b>	<b>Has he/she ever had a nervous or emotional illness requiring treatment?</b> (Record number of illnesses)	No .....	2	7
		1 episode .....	0	8
		2 episodes .....	1	
		3 episodes .....	3	
		4 episodes .....	4	
		5 episodes .....	5	
		6 or more episodes .....	6	

**Did any of his/her close relatives have trouble with memory or get very confused and have to go into a home to be looked after?**

<b>318.</b>	<b>Female relatives: mother, sisters, daughters</b>	Number _____	77
		None .....	00 88
<b>319.</b>	<b>Male relatives: father, brothers, sons</b>	Number _____	77
		None .....	00 88

**19. Many services are available to help elderly people and those who care for them. Services may be provided by the government, hospitals, private agencies or volunteer agencies. You have probably heard of some of these: for example, Homemaker Services, In-Home Nursing, or Self-Help Groups.**

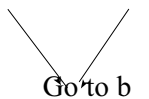

**I am going to read you a list of statements about community services and I would like you to tell me how strongly you agree or disagree with each statement.**

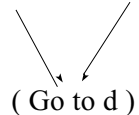
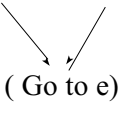
(CUE CARD #3)

1	Strongly Disagree	2	Disagree	7	R
3	Agree	4	Strongly Agree	8	DK

- a) **I would rather ask my family or friends for help than use community services** \_\_\_\_\_
- b) **I believe the government should support more community services to help care for people at home** \_\_\_\_\_
- c) **I am proud of being able to care for my relative with little help from community services** \_\_\_\_\_
- d) **I believe in the idea that families should care for their own and not ask for outside help** \_\_\_\_\_
- e) **No-one has told me what services are available for my relative** \_\_\_\_\_
- f) **I wish there were someone who could tell me more about community services for my relative** \_\_\_\_\_
- g) **I do not have time or energy to look for community services for my relative** \_\_\_\_\_
- h) **I have been meaning to look for services but have not gotten around to it** \_\_\_\_\_

20. Now I want to ask you about assistance or community services that (\_\_\_\_) or his/her family may have been using in the past year. I am going to read a list of services, and for each, I am going to ask you whether or not they have been used to help (\_\_\_\_) and his/her family.

Name of service	A. Has the service been used by (____) in past year?	B. How many times in past year?	C. (If not used)
a. Homemaker	1 Yes (→ B) 2 No (→ C)  7 R 8 DK  Go to b	_____  On regular basis (e.g., once a week)?  1 Regular 2 Occasional 7 R 8 DK	1. Is this service available in your area? 1 Yes 2 No (Go to 20b) 7 R 8 DK 2. Do you or (____) need this service? 1 Yes (Go to C3) 2 No 7 R 8 DK IF No and no explanation given: Why do you say that?  3. Is there a reason why you did not use a homemaking service? For example, cost, waiting lists, you or (____)'s preference?
b. Home delivered meals	1 Yes (→ B) 2 No (→ C)  7 R 8 DK  Go to c	_____  On regular basis (e.g., once a week)?  1 Regular 2 Occasional 7 R 8 DK	1. Is this service available in your area? 1 Yes 2 No (Go to 20c) 7 R 8 DK 2. Do you or (____) need this service? 1 Yes (Go to C3) 2 No 7 R 8 DK IF No and no explanation given: Why do you say that?  3. Is there a reason why you did not use home delivered meals? For example, cost, waiting lists, you or (____)'s preference?

Name of service	A. Has the service been used by (____) in past year?	B. How many times in past year?	C. (If not used)
<b>c. Home help for personal tasks (e.g. grooming, bathing)</b>	1 Yes (→ B) 2 No (→ C)  7 R 8 DK  ( Go to d )	_____  On regular basis (e.g., once a week)?  1 Regular 2 Occasional 7 R 8 DK	<b>1. Is this service available in your area?</b> 1 Yes 2 No (Go to 20d) 7 R 8 DK <b>2. Do you or (____) need this service?</b> 1 Yes (Go to C3) 2 No 7 R 8 DK If No and no explanation given: <b>Why do you say that?</b>  <b>3. Is there a reason why you did not use a home help? For example, cost, waiting lists, you or (____)'s preference?</b>
<b>d. In-home nursing care</b>	1 Yes (→B) 2 No (→C)  7 R 8 DK  ( Go to e )	_____  On regular basis (e.g., once a week)?  1 Regular 2 Occasional 7 R 8 DK	<b>1. Is this service available in your area?</b> 1 Yes 2 No (Go to 20e) 7 R 8 DK <b>2. Do you or (____) need this service?</b> 1 Yes (Go to C3) 2 No 7 R 8 DK If No and no explanation given: <b>Why do you say that?</b>  <b>3. Is there a reason why you did not use in-home nursing? For example, cost, waiting lists, you or (____)'s preference?</b>

Name of service	A. Used by (_____) in past year?	B. How many times in past year?
<b>e. Physiotherapy (in the home or at a clinic)</b>	1 Yes → 2 No } 7 R } (Go to f) 8 DK }	_____ 7 R 8 DK
<b>f. Occupational therapy (in the home or at a clinic)</b>	1 Yes → 2 No } 7 R } (Go to g) 8 DK }	_____ 7 R 8 DK
<b>g. Podiatry treatments</b>	1 Yes → 2 No } 7 R } (Go to h) 8 DK }	_____ 7 R 8 DK
<b>h. Chiropractic treatments</b>	1 Yes → 2 No } 7 R } (Go to i) 8 DK }	_____ 7 R 8 DK
<b>i. Day centre</b>	1 Yes → 2 No } 7 R } (Go to j) 8 DK }	_____ 7 R 8 DK

The next questions will ask about services that you, the caregiver, may have used to help you.

Name of service	A. Have you used ( <i>the service</i> ) in past year?	B. How many times in past year?
<b>j. Respite care for ( _____ ) in home</b>	1 Yes → 2 No } 7 R } (Go to k) 8 DK }	_____  7 R 8 DK
<b>k. Respite care for ( _____ ) in hospital or nursing home</b>	1 Yes → 2 No } 7 R } (Go to l) 8 DK }	_____  7 R 8 DK
<b>l. Information or support service (e.g. the Web, Alzheimer Society, the Arthritis Society)</b>	1 Yes → 2 No } 7 R } (Go to m) 8 DK }	_____  7 R 8 DK
<b>m. Self-help or support group</b>	1 Yes → 2 No } 7 R } (Go to n) 8 DK }	_____  7 R 8 DK
<b>n. Phone help lines</b>	1 Yes → 2 No } 7 R } (Go to o) 8 DK }	_____  7 R 8 DK
<b>o. Advice or guidance from a physician or social worker</b>	1 Yes → 2 No } 7 R } (Go to p) 8 DK }	_____  7 R 8 DK
<b>p. Counselling from a physician or psychologist</b>	1 Yes → 2 No } 7 R } (Go to Q. 21) 8 DK }	_____  7 R 8 DK

IF no services used, go to Q.22.

IF services used: **Now, I would like to ask a question about the cost of these services:**

**21. Thinking of all of these services, how much do you or the family pay per month in out-of-pocket expenses?**

\$ \_\_\_\_\_                      7 R                      8 DK

**22. Are you or your family contributing to any additional costs of care (for example, paying for parking at doctors and hospitals, home adaptations, special diets)?**

1 Yes                      2 No                      7 R                      8 DK

If YES ask: **How much does this cost in total per month?** \$ \_\_\_\_\_

**23. Now I would like you to think about services or assistance you or (\_\_\_\_) are not currently receiving. Are there any services or other forms of assistance that would help you in caring for (\_\_\_\_)?**

(Do not read alternatives. Circle all that apply)

- |  |  |
|--|--|
| 0 None   | 9 Counselling from a social worker or psychologist |
| 1 Homemaker service  | 10 Self-help or support groups                     |
| 2 Home delivered meals   | 11 Clergy  |
| 3 Help for personal tasks  | 12 Aids for handicapped people                     |
| 4 In-home nursing care   | 13 Help with transportation                        |
| 5 Physiotherapy, occupational therapy, podiatry or chiropractic treatments | 14 House and yard maintenance                      |
| 6 Day centre or day hospital   | 15 Social visits                                   |
| 7 Hospital or nursing home for respite care                                | 20 Other specify: _____                            |
| 8 In-home respite care   | 77 R   |
|  | 88 DK  |





**24d. During the past year, did you have to take time off from work because of your own health problems?**

1 Yes                      2 No                      7 R                      8 DK

If YES:

**d1. Approximately how many days were you absent due to these health problems during the past year?**

Number of days: \_\_\_\_\_ Days                      777 R                      888 DK

**24e. Aside from the days that you missed, did your health problems limit your productivity at work during the last year?**

1 Yes                      2 No (Go to Q. 24f)                      7 R (Go to Q. 24f)                      8 DK (Go to Q. 24f)

If YES:

**e1. How many days was your working capacity reduced during the past year?**

Number of days: \_\_\_\_\_ Days                      777 R                      888 DK

**e2. By what percentage do you think that your working capacity was reduced?**

\_\_\_\_\_ (%)                      777 R                      888 DK

**24f. Because of caring for (\_\_\_\_), have you: (READ ALL)**

	Yes	No	R	DK
Changed jobs or employers?	1	2	7	8
Declined a job advancement? (transfer or promotion)	1	2	7	8
Increased the hours you worked?	1	2	7	8
Had to come late to work?	1	2	7	8
Changed the shift you worked?	1	2	7	8
Needed to leave work for doctor's appointment pertaining to (____)?	1	2	7	8
Been interrupted frequently by phone calls from or pertaining to (____)?	1	2	7	8

---

If the caregiver is presently working for pay, Go to Q. 25

**24g. When did you last work?**

Specify year: \_\_\_\_\_ 7777 R 8888 DK  
9997 Never worked (Go to Q. 25)

**24h. Why did you stop working?** (Circle answers they mention: do not read)

- |   |                          |      |                        |
|---|--------------------------|------|------------------------|
| 1 | To care for (_____)      | 6    | Early retirement       |
| 2 | Reached retirement age   | 7    | Company closed         |
| 3 | Own health problems      | 8    | Other (specify): _____ |
| 4 | Other family commitments |      |                        |
| 5 | Laid off, fired          | 77 R | 88 DK                  |

**CAREGIVER’S HEALTH**

Now, I would like to talk with you about your health and how you have been feeling.

25. In general, would you say your health is:

(SHOW CARD #4) (circle one)

1 Excellent 2 Very Good 3 Good 4 Fair 5 Poor 7 R 8 DK

26. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)  (SHOW CARD #5)

Activities	Yes, limited a lot	Yes, limited a little	No, not at all	R	DK
a) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	7	8
b) Climbing several flights of stairs	1	2	3	7	8

27. During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line)

	Yes	No	R	DK
a) Accomplished less than you would like	1	2	7	8
b) Were limited in the kind of work or other activities you could do.	1	2	7	8

28. During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)? (circle one number on each line)

	Yes	No	R	DK
a) Accomplished less than you would like	1	2	7	8
b) Didn't do work or other activities as carefully as usual	1	2	7	8

29. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?  (SHOW CARD #6)

1 Not at all 2 A little bit 3 Moderately 4 Quite a bit 5 Extremely 7 R 8 DK

30. These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS -  (SHOW CARD #7)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	R	D K
a) Have you felt calm and peaceful?	1	2	3	4	5	6	7	8
b) Did you have a lot of energy?	1	2	3	4	5	6	7	8
c) Have you felt downhearted and blue?	1	2	3	4	5	6	7	8

31. DURING THE PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?  (SHOW CARD #8)

- |                    |                        |
|--------------------|------------------------|
| 1 All of the time  | 4 A little of the time |
| 2 Most of the time | 5 None of the time     |
| 3 Some of the time | 7 R                    |
|                    | 8 DK                   |

**32. Now I will read you a list of ways you might have felt IN THE PAST WEEK. As I read each statement, please tell me how often you felt this way during the PAST WEEK: Rarely, Some of the time, a Moderate amount of the time, or Most of the time. ☐ (SHOW CARD #9)**

- 0 Rarely or none of the time (for less than 1 day in past week)
- 1 Some or a little of the time (1-2 days)
- 2 Occasionally or a moderate amount of the time (3-4 days)
- 3 Most or all of the time (5-7 days)
- 7 R
- 8 DK

During the past week	Rarely	Some	Occasionally	Most	R	DK
a) I was bothered by things that don't usually bother me	0	1	2	3	7	8
b) I had trouble keeping my mind on what I was doing	0	1	2	3	7	8
c) I felt depressed	0	1	2	3	7	8
d) I felt that everything I did was an effort	0	1	2	3	7	8
e) I felt hopeful about the future	0	1	2	3	7	8
f) I felt fearful	0	1	2	3	7	8
g) My sleep was restless	0	1	2	3	7	8
h) I was happy	0	1	2	3	7	8
i) I felt lonely	0	1	2	3	7	8
j) I could not get going	0	1	2	3	7	8

**33. Many people report that they experience positive or rewarding aspects of caregiving. I would like you to think about any enjoyable or positive features you find in being a caregiver. Do you find any positive aspects of caregiving?**

- 1 Yes 7 R } Go to Q. 34
- 2 No (Go to Q.34) 8 DK }

If YES:

**33a. Could you briefly tell me what some of these are?**

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**34. Finally I would like to ask about your income. What you tell me is confidential information.**

Think about your household income from all sources (for example, jobs, social security).

Which category does your income fall into?  (SHOW CARD #10)

1  2  3  4  5  6  7  8  9  10  11  12

77  R

88  DK

**35. In order to complete the health service utilization component of our study, we would very much appreciate your consent to access your Provincial health plan records. Please remember, all information will be confidential as described on the consent form.**

(Present Caregiver with the copy of the consent form to access their provincial health records.)

**Consent given for Caregiver's own records:** 1 Yes 2 No

**Conclusion** This is the end of the interview. Thank you very much for your help and your patience. This completes your participation in the Canadian Study of Health and Aging. We are very grateful for your assistance.

⌚ Interview End Time: \_\_\_\_\_ : \_\_\_\_\_ (Please use 24 hr clock)

**Housing arrangements of subject**

- |                        |                         |
|------------------------|-------------------------|
| 1 Detached             | 6 Seniors' residence    |
| 2 Semi-detached        | 7 Other (specify _____) |
| 3 Apartment or condo   | 8 Don't know            |
| 4 Highrise             | 9 Missing               |
| 5 Guest/Boarding House |                         |

**Place of interview**

- 1 Respondent's Home  
 2 Subject's Home  
 3 Other (Specify): \_\_\_\_\_

This questionnaire, (items number 25-31), includes the SF-12 Health Survey, reproduced with permission of Health Assessment Lab. Copyright 1994

**ADL/IADL Summary Information Sheet**  
 (to be filled out by interviewer after Caregiver/Informant Interview  
 and passed on to clinician before clinical exam)

ADL/IADL activity	Does the subject have difficulty with this activity? (Difficulty includes 'needs some help' as well as 'completely unable to do')	
	Yes	No
Eating (Feeding)		
Dressing and undressing		
Taking care of appearance		
Walking		
Getting in and out of bed		
Taking a bath or shower		
Toileting		
Using telephone		
Getting to places out of walking distance		
Shopping		
Preparing meals		
Housework		
Taking medicine		
Handling money		

**INTERVIEWER SUMMARY OF CAMDEX**

Completed by interviewer after interview

**Part I: Questions concerning recent history**

	<u>IF problem recorded, specify question</u>		
<b>Personality (238-244)</b>	238 Personality 241 Irritability	239 Exaggeration PFQ1 Aggressive	240 Changeable 244 Stubborn
<b>Memory (247-251)</b>	247 Recalling short list 249 Interpreting surroundings 251 Finding way in neighbourhood	248 Recent events 250 Finding way in house	
<b>General Intellectual functioning (254 - PFQ2)</b>	254 General decline 257 Decision making PFQ2 Train of thought	255 Dwells on past 258 Special skills	256 Finding words 259 Muddled
<b>Paranoid Traits (286 - 287)</b>	PFQ3 Suspicious	286 Persecution	287 Voices
<b>Clouding / delirium (271 - 274)</b>	271 Days/weeks	272 24 hrs.	273 Sundown
<b>Depressive symptoms (275 - 276)</b>		275 Lost interest	276 Depressed
<b>Sleep (283)</b>	283 Wanders at night		
<b>Cerebrovascular problems (288 - 290)</b>	288 Passed out	289 Falls	290 Stroke
<b>General Summary (292)</b>		292 Difficulty getting about	



**Part II: Past History**

Yes    No    IF YES ,please specify

**A) Illnesses**

(Questions 295 - 302,  
and 308 - 309)

1

2

\_\_\_\_\_

\_\_\_\_\_

**B) Lifestyle habits (303 - 307)**

303 Smoking

304 Alcohol

305 Heavy drinker

306 Alcohol problems

307 Drugs

\_\_\_\_\_

Yes    No

**Cognitive losses/problems**

(318 - 319)

1

2

**Other comments:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_