

Medical Research Council  
Cognitive Function and Ageing Study  
(MRC CFAS)

Retrospective Informant Interview

Centre:

Project Number:

Interviewer:

Date of Interview:

Time Interview started:

*Please note: Local decisions will be made on the appropriate interval which should elapse before approach for a RInI.*

*It is recommended that the birthday of the deceased and the anniversary of death be avoided.*

*It may be helpful to consult any available documentation. e.g. DOI approach sheet, notes on brain collection, report/letter from pathologist, interviewer vignettes, etc.*

Final version 09/97

My name is ..... I'm an interviewer with ..... (local name of study), in which ..... (name of subject) kindly took part. (GIVE MORE INFORMATION ABOUT THE STUDY AS APPROPRIATE - MAY BE GIVE A COPY OF THE NEWSLETTER).

You may be aware that she/he generously donated brain tissue on her/his death. We value this gift highly. Our research programme aims to look at normal brain ageing as well as that which leads to frailty. When we examine the donated tissue, we find it extremely helpful to have some information about the final years of the donor's life. We wondered if you would be willing to answer some questions about this period.

I appreciate that this may upset or distress you, and would be happy to carry out the interview at your convenience. All the information collected is strictly confidential, and will be held anonymously on our data files.

The interview should take about 30 minutes.

Firstly, I'd like to ask a few questions about you.

Q1 How old are you?  
Age in years      nnn

Q2 RATE: SEX OF INFORMANT  
Male              1  
Female            2

- Q3 What was your relationship to ..... (subject)
- |                              |   |
|------------------------------|---|
| Spouse                       | 1 |
| Sister / Brother             | 2 |
| Sister-in-law/Brother-in-law | 3 |
| Son/daughter                 | 4 |
| Son-in-law/Daughter-in-law   | 5 |
| Friend                       | 6 |
| Caregiver/Warden             | 7 |
| Other (specify)              | 8 |

- Q4 How long had you known him/her?
- Number of years (and months) yy.mm

- Q5 And how often did you see him/her?
- (IN RECENT YEARS - NOT INCLUDING INCREASED FREQUENCY OF CONTACT IN RESPONSE TO FINAL ILLNESS)
- |                       |   |
|-----------------------|---|
| Lived with            | 1 |
| Daily                 | 2 |
| More than once a week | 3 |
| Weekly                | 4 |
| Monthly               | 5 |
| Yearly                | 6 |

**And now some general questions about ..... (subject)**

- Q6 Are either of his/her parents still alive?  
IF FATHER NOT ALIVE: How old was his/her father when he died?

000 Still alive  
nnn Age at death

- Q7 IF MOTHER NOT ALIVE: How old was his/her mother when she died?

000 Still alive  
nnn Age at death

- Q8 Did s/he have any brothers or sisters?  
IF YES: How many? (INCLUDE BROTHERS AND SISTERS WITH AT LEAST ONE PARENT IN COMMON WITH (subject). INCLUDE THOSE WHO HAVE DIED)

nn Number of siblings, excluding subject

IF NO SIBS SKIP TO Q12

Q9 How many of them are still alive?

nn Number of siblings still alive, excluding subject

IF NONE ALIVE, SKIP TO Q11

Q10 And how many of them have reached the age of 70 years?

nn Number still alive, aged 70+

IF NONE HAVE DIED, SKIP TO Q12

Q11 And of those who have died, did any reach the age of 70 years?

nn Number died, aged 70+

Q12 Can you tell me what was ..... (subject's) occupation for most of his/her working life?

a. PROBE FOR: Job Title:

b. Type of industry/organisation:

c. Self employed: No 0  
Yes 1

d. Number of people employed at that place:  
1-24 1  
25+ 2

e. Status: Neither 0  
Foreman/supervisor 1  
Manager 2

f. Responsible for: None 0  
1-24 1  
25+ 2

Q13 How many years did s/he spend in full time education?

Number of years nn

Q14 Did s/he do any further training such as a college course or an apprenticeship?

None 0  
LEAVE BLANK School leaving certificate 1  
IF NOT KNOWN Technical college exams 2  
Secretarial college exams 3  
Completed apprenticeship 4  
Trade certificates (electrician/plumber etc.) 5  
Higher professional qualification 6  
excluding university degree  
University degree 7  
Other (specify) .....

Q15 What was the best job s/he ever held? (Not necessarily the best paid, but the one with most responsibility)  
(SPECIFY JOB REQUIRING HIGHEST INTELLECTUAL ABILITY, WHICH WAS HELD FOR 2 YEARS OR MORE.  
GIVE JOB TITLE AND ORGANISATION)

**And now some questions about ..... (subject's) final illness.**

Q16 Do you know what he/she died from?  
Heart attack 1  
Chest infection 2  
Stroke 3  
Cancer 4  
Other (specify) 5  
Specify.....

Q17 In the 2 years before he/she died, did he/she develop any other health problems that you know of?  
No 0  
Yes 1  
Specify: .....

Q18 UNLESS THE DEATH IS UNEXPECTED AND VERY QUICK, FOR MOST PEOPLE THERE IS A CLEAR PERIOD  
(WHICH CAN BE DAYS, WEEKS OR MONTHS) WHICH LEADS DIRECTLY TO THE DEATH OF THE INDIVIDUAL. WE ARE  
LOOKING TO IDENTIFY DECLINE BEFORE THIS PERIOD.

SPECIFY FINAL ILLNESS.

.....

Q19 For how long did his/her final illness last?  
Sudden death 0  
Less than 1 week 1  
7 days up to 1 month 2  
1 month up to 1 year 3  
1 year 4  
1-2 years 5  
2 years or more 6

IF SUDDEN DEATH SKIP TO Q21

Q20 Did s/he get steadily worse, remain about the same or were there times when his/her condition improved?  
Same or little change 0  
Some improvement 1  
Steadily worse 2  
Sudden death 8 (not applicable)

Q21 Where was s/he living before the final illness? (or sudden death)  
At home alone 1  
At home with spouse or other 2  
At home with relatives 3  
Sheltered housing 4  
Residential Home 5  
Nursing Home 6  
Long-term hospital bed 7

Acute hospital bed	8
Hospice	9
Other (specify).....	

IF SUDDEN DEATH SKIP TO Q23

Q21a Did s/he subsequently move to other accommodation?

No	0
Yes	1

Q22 To where did s/he move?

First move \*(put number from Q22)

At home alone	1
At home with spouse	2
Moved into relatives home	3
Sheltered Housing	4

Second move\*

Residential Home	5
Nursing Home	6
Long-term hospital bed	7

Third move\*

Acute hospital bed	8
Hospice	9
Other (specify).....	

Final move\*

THE REST OF THE INTERVIEW ASKS ABOUT THE PERIOD BEFORE ONSET OF THIS FINAL ILLNESS. WE ARE INTERESTED IN CHARACTERISING THE WORST LEVEL OF IMPAIRMENT THAT THE SUBJECT REACHED PRIOR TO THEIR FINAL ILLNESS.

FOR EXAMPLE, IF, 3 MONTHS PRIOR TO DEATH, THE SUBJECT WAS SEVERELY DISABLED BY TERMINAL STAGE OF CANCER OR AN EVENT SUCH AS STROKE CLEARLY LINKED TO SUBSEQUENT DEATH, WE WANT TO KNOW HOW THEY WERE FUNCTIONING UP TO THE TIME OF THE STROKE.

**I would now like to ask you about changes which might have occurred during the last years of his/her life (but before the final illness).**

**Personality**

IT MAY BE NECESSARY TO INTRODUCE EACH SECTION IN YOUR OWN WAY: FOR EXAMPLE, "SOMETIMES PEOPLE DEVELOP DIFFICULTY WITH EVERYDAY ACTIVITIES" COULD INTRODUCE THE SECTION ON 'DAILY ACTIVITIES'. KEEP REMINDING **"that is prior to ..... (the final illness)"**.

During this time.....

Q23 Did you notice any changes in his/her personality, such as the way s/he behaved socially?  
No 0  
Yes 1

Specify type of change  
.....

Q24 Was there any noticeable exaggeration in his/her normal character?  
No 0  
Yes 1

Q25 Did s/he become more (or less) changeable in mood?  
No 0  
Less 1  
More 2

Q26 Did s/he become more (or less) irritable or angry?  
No 0  
Less 1  
More 2

Q27 Did s/he show less concern for others? Or more?  
No 0  
Less 1  
More 2

Q28 Had there been a change in behaviour, perhaps doing embarrassing things, or tending to hurt or upset people?  
No 0  
Yes 1

Q29 Did s/he seem more unconcerned about how to behave in certain situations than s/he used to? Did s/he seem unaware of how others felt about her/his behaviour?  
No 0  
Yes 1

Specify any inappropriate behaviour  
.....

Q30 Did s/he become more stubborn or perhaps a little awkward? Or less?  
No 0  
Less 1  
More 2

IF NO PERSONALITY CHANGE (Q23-30), SKIP TO Q35

Q31 How long had any of these changes been present? (AT ANY TIME IN THE PAST)  
 Duration in months nnn  
 All the time I've known him/her 666

Q32 Did these changes develop gradually or did they come on suddenly?  
 Gradual 0  
 Sudden 1

Q33 Did you think s/he was aware of this problem (these problems)?  
 Good insight 0  
 Some insight 1  
 No insight 2

Q34 Do you think there was anything specific that caused these changes?  
 No 0  
 Yes 1

IF YES: Specify

.....

### Memory

(STILL REFERRING TO THE LAST YEARS OF LIFE, PRIOR TO FINAL ILLNESS)

Q35 Did s/he have difficulty remembering recent events, e.g. when s/he last saw you, or what happened the day before?

No difficulty 0  
 Slight difficulty 1  
 Great difficulty 2

Q36 Did s/he have difficulty remembering names of family and close friends?

No 0  
 Occasionally 1  
 Frequently 2

Q37 Did s/he forget what had been said and repeated the same question over and over?

No 0  
 Occasionally 1  
 Frequently 2

Q38 Did s/he have difficulty in interpreting surroundings, e.g. knowing where s/he was, or discriminating between different types of people, such as doctors, visitors and relatives?

No difficulty 0  
 Slight difficulty 1  
 Great difficulty 2

Q39 Did s/he have more difficulty in remembering short lists of items e.g. when shopping?

Same as usual 0  
 Slightly more difficulty 1  
 A great deal more difficulty 2

Q40 Did s/he have difficulty finding the way around the neighbourhood, e.g. to the shops or Post office near home?

No difficulty	0
Slight difficulty	1
Great difficulty	2
HOUSEBOUND	9

Q41 Did s/he have difficulty finding the way about the home (or ward) or finding the toilet?

No difficulty	0
Slight difficulty	1
Great difficulty	2
BEDFAST	9

IF NO MEMORY PROBLEMS (Q35-41), SKIP TO Q46

Q42 How long had these changes or difficulties been present?

Duration in months	nnn
All the time I've known him/her	666

IF Q42 = 666 SKIP TO 44

Q43 Did these changes or difficulties develop gradually or did they come on suddenly?

Gradual	0
Sudden	1

Q44 Do you think s/he was aware of the memory problem(s)?

No	0
Yes	1

Q45 Do you think there was anything specific that caused these changes?

No	0
Yes	1

IF YES: Specify

.....

### General mental functioning

Q46 Aside from memory, was there a more general decline in his/her mental functioning? For example, was his/her thinking less sharp?

No	0
Yes	1

Q47 Did s/he have greater difficulty thinking ahead and planning for the future than s/he used to? (How big a problem was that?)

No	0
Mild	1
Severe	2



Q48 Did s/he find it difficult to keep his/her mind on things more than s/he used to? Was s/he more easily distracted? (How big a problem was that?)

No	0
Mild problem	1
Severe problem	2

Q49 Did s/he act more impulsively than s/he used to by doing the first thing that came to mind? (How big a problem was that?)

No	0
Mild	1
Severe	2

Q50 Did s/he talk very much more or very much less than s/he used to do?

No change	0
Talked less, but not mute	1
Nearly or completely mute	2
Talked more	3

Q51 Did s/he tend to talk about what happened long ago rather than in the present?

No	0
Sometimes	1
Often	2

Q52 When speaking, did s/he have difficulty finding the right word, or use wrong words?

No	0
Yes	1

Q53 Did s/he repeat the same word or phrase over and over again?

No perseveration	0
Perseveration	1

Q54 Did s/he seem to find it more difficult to make decisions?

No	0
Yes	1

Q55 Was there a loss of any special skill or hobby s/he could manage before?

(RATE FOR SKILLS OR HOBBIES ABANDONED BECAUSE OF COGNITIVE DISABILITY. E.G. LACK OF CONCENTRATION)

No	0
Yes	1

Q56 Did his/her thinking seem muddled?

No	0
Yes	1

IF NO MENTAL DETERIORATION (Q46-56), SKIP TO Q62

Q57 How long had these changes or difficulties been present?  
 Duration in months nnn  
 All the time I've known him/her 666

IF Q57 = 666 SKIP TO Q60

Q58 Did this difficulty develop in a gradual manner or did it come on suddenly?  
 Gradual 0  
 Sudden 1

Q59 Did this difficulty develop in steps and stages?  
 No 0  
 Yes 1

Q60 Did s/he realise the extent of his/her problems?  
 Good insight 0  
 Some insight 1  
 No insight 2

Q61 Do you think there was anything specific that caused these changes?  
 No 0  
 Yes 1

IF YES: Specify

.....

**Everyday activities**

Q62 Did s/he have any difficulty in performing common household tasks, e.g. could s/he make a cup of tea?  
 No difficulty 0  
 Slight difficulty 1  
 Great difficulty 2

IF YES: Was this due to physical illness?

Not due to physical illness 0  
 Partly due to physical illness 1  
 Entirely due to physical illness 2

Q63 Did s/he have difficulty in managing small amounts of money?  
 No more difficulty 0  
 Slight difficulty 1  
 Great difficulty 2

IF YES: Was this due to physical illness?

Not due to physical illness 0  
 Partly due to physical illness 1  
 Entirely due to physical illness 2

Q64	Did s/he have difficulty in feeding him/herself?		
	No difficulty		0
	Messily with a spoon only		1
	Simple solids, e.g. biscuits		2
	Has to be fed		3
	IF YES: Was this due to physical illness?		
	Not due to physical illness		0
	Partly due to physical illness		1
	Entirely due to physical illness		2
Q65	Did s/he sometimes try to eat far too much food or drink too much? (Did s/he eat a great deal more than s/he used to?)		
	No		0
	Yes		1
Q66	Did s/he sometimes try to eat peculiar things, such as soap, cigarettes or dirt?		
	No		0
	Yes		1
Q67	Did s/he have difficulty in dressing?		
	No difficulty		0
	Occasionally misaligned buttons etc.		1
	Wrong sequence, often forgot items		2
	Unable to dress self		3
	IF YES: Was this due to physical illness?		
	Not due to physical illness		0
	Partly due to physical illness		1
	Entirely due to physical illness		2
Q68	Did s/he wet or soil him/herself?		
	No		0
	Wet occasionally		1
	Wet often		2
	Doubly incontinent		3
	IF YES: Was this due to physical illness?		
	Not due to physical illness		0
	Partly due to physical illness		1
	Entirely due to physical illness		2
	IF NONE OF Q62-68 PRESENT, SKIP TO Q71		
Q69	How long had these difficulties been present?		
	Duration in months		nnn
	All the time I've known him/her		666

Q70 Did these difficulties develop gradually or did they come on suddenly?  
 Gradual 0  
 Sudden 1

**Clouding/delirium**

STILL REFERRING TO LAST YEARS OF LIFE, PRIOR TO FINAL ILLNESS.

Q71 Had there been an abrupt change towards mental confusion in the period before the final illness?  
 No 0  
 Yes 1  
 Uncertain 2

IF 'YES' OR UNCERTAIN ASK Qs72-78. IF 'NO' SKIP TO Q79

Q72 Were there periods lasting days or weeks when his/her thinking still seemed quite clear?  
 No 0  
 Yes 1

Q73 Were there brief episodes during 24 hours when s/he seemed much worse and then times when quite clear?  
 No 0  
 Yes 1

Q74 Did s/he become completely normal when the confusion cleared?  
 No 0  
 Yes 1

Q75 Was the confusion worse towards dusk or evening?  
 No 0  
 Yes 1

Q76 Were there marked fluctuations in his/her level of attention or alertness?  
 No 0  
 Yes 1

Q77 How long had the confusion been present?  
 Duration in months nnn  
 All the time I've known him/her 666

Q78 Do you think there was anything specific that caused these changes?  
 No 0  
 Yes 1

IF YES: Specify

.....

**Depressed mood**

Q79 Was there a loss of interest or enjoyment in things in general?

No	0
Yes	1

Q80 Was s/he (more or) less sociable than s/he used to be? E.g. had s/he lost interest in meeting people and going out? (How big a problem was that?)

No change	0
More social	1
Less sociable but some social interaction	2
Much less sociable, little or no interaction	3

Q81 Was s/he inclined to blame him/herself or feel unreasonably guilty?

No	0
Yes	1

Q82 Do you think s/he was depressed?

No	0
Yes	1

IF NO DEPRESSION (Q79-83), SKIP TO Q88

Q83 Do you think there was a reason for the depression?

No	0
Yes	1

IF YES: Specify

.....

Q84 Was the depression so bad that it affected every part of his/her life, work, friendship, family life?

No	0
Yes	1

Q85 How long had this been present?

Duration in months	nnn
All the time I've known him/her	666

IF Q85=666 SKIP TO Q87

Q86 Did this develop gradually or come on suddenly?

Gradual	0
Sudden	1

Q87 Did you think s/he was aware of being depressed?

Good insight	0
Some insight	1
No insight	2

**Sleep**

Q88 Did s/he have difficulty getting to sleep?

No 0  
Yes 1

Q89 Was s/he restless or wakeful during the night?

No 0  
Yes 1

Q90 Did s/he tend to get up and wander at night or any other time?

No 0  
Yes 1

Q91 Did s/he wake early in the morning, before her/his normal time, and not get back to sleep again?

No 0  
Yes 1

Q92 Did s/he sleep much more than usual for him/her?

No 0  
Yes 1

IF NO DIFFICULTIES (Q88-92), SKIP TO Q96

Q93 How long had this difficulty (these difficulties) been present?

Duration in months nnn  
All the time I've known him/her 666

Q94 Did this (they) come on gradually or develop suddenly?

Gradual 0  
Sudden 1

Q95 Do you think there was anything specific that caused these sleep problems?

No 0  
Yes 1

IF YES: Specify

.....

**Paranoid features**

Q96 Did s/he complain unjustifiably of being persecuted or spied upon?

No 0  
Yes 1

Q97 If yes, for how long?

Duration in months nnn  
All the time I've known him/her 666

Q98 Was s/he troubled by voices or visions not experienced by others?  
 No 0  
 Yes 1

IF Q98 = 0 SKIP TO Q101

Q99 For how long?  
 Duration in months nnn  
 All the time I've known him/her 666

Q101 Do you think there was anything specific that caused these problems?  
 No 0  
 Yes 1

IF YES: Specify

.....

**Cerebrovascular problems**

Q102 During the period before the final illness, did s/he 'pass out' and then have a brief weakness or difficulty with speech, memory or vision?

No 0  
 Yes 1

IF NO SKIP TO Q104

Q103 How long before death did it first occur?  
 RECORD TIME IN MONTHS nnn  
 Prior to my knowing him/her 666

Q104 Did s/he fall or come close to falling?  
 No 0  
 Yes 1

IF NO SKIP TO Q106

Q105 How long before death did that first occur?  
 RECORD TIME IN MONTHS nnn  
 Prior to my knowing him/her 666

Q106 Did s/he ever have a stroke?

NB Q ASKS 'EVER HAD A STROKE'

No 0  
 One 1  
 Two 2  
 More than two 3

IF NO STROKES SKIP TO Q109

Considering the first stroke, how was s/he affected?

Impairment right side	1
Impairment left side	1
Speech affected	1
Other (specify)	1

.....

How much recovery was there?

None	0
Partial	1
Complete	2

Further details:  
.....

Q107 How long before death did the first stroke occur?

RECORD TIME IN MONTHS	nnn
Prior to my knowing him/her	666

Considering the second stroke, how was s/he affected?

Impairment right side	1
Impairment left side	1
Speech affected	1
Other (specify)	1

.....

How much recovery was there?

None	0
Partial	1
Complete	2

Further details:  
.....

Considering the last stroke, how was s/he affected?

Impairment right side	1
Impairment left side	1
Speech affected	1
Other (specify)	1

.....

How much recovery was there?

None	0
Partial	1
Complete	2

Further details:  
.....

IF THERE WERE NO STROKES SKIP TO Q109

Q108 Did the changes you've mentioned earlier seem to start after the stroke/these episodes?

No	0
Yes	1

ENTER ANY COMMENTS:  
.....



**General summary**

IF NO PROBLEM HAS BEEN ESTABLISHED ANYWHERE IN THE INFORMANT INTERVIEW (QUESTIONS 23-108), CODE 9 OR 999 BELOW.

Q109 Did s/he have trouble getting about since the onset of the difficulties you've mentioned?

No	0
Some trouble	1
Great trouble	2

IF YES: Was this due to physical illness?

Not due to physical illness	0
Partly due to physical illness	1
Entirely due to physical illness	2

Q110 Was s/he more restless than s/he used to be? For example, did s/he find it hard to sit still for any length of time? (How big a problem was this?)

No	0
Mild problem	1
Severe problem	2

IF YES: Was this due to physical illness?

Not due to physical illness	0
Partly due to physical illness	1
Entirely due to physical illness	2

ASK AS APPROPRIATE

Q111 From what you have told me, there were some changes in ..... (subject). Can you tell me what was the first change you noticed in his/her behaviour?

RECORD ANSWER IN FULL

.....

Q112 How long before his/her death was that?

Length of time before death in months      mmm

Q113 In your judgement, when was the last time his/her mental ability was normal? That would be how many months prior to death?

RATE: Length of time before death in months      mmm

Q114 Before his/her final illness (but not including the final illness) did s/he have:

a. Angina?	No	0
	Yes	1
b. Heart attack?	No	0
	Yes	1
c. Problems with circulation in legs?	No	0
	Yes	1

d. High blood pressure?	No	0
	Yes	1
e. Chronic bronchitis?	No	0
	Yes	1
f. Parkinson's Disease?	No	0
	Yes	1
g. Tremor or rigidity, <u>not due to joint problems / arthritis?</u>	No	0
	Action tremor	1
	Resting tremor	2
	Both	3
	Rigidity	4
h. A fixed facial expression showing less emotion than before?	No	0
	Yes	1
i. An acute illness after being given some new medication?	No	0
	Yes	1
j. Sugar diabetes?	No	0
	Yes	1
k. Thyroid problems?	No	0
	Yes	1
l. Severe headaches or migraine?	No	0
	Yes	1
m. A serious head injury with a period of unconsciousness?	No	0
	Yes	1
n. An epileptic fit?	No	0
	Yes	1
o. A nervous or emotional illness requiring treatment?	No	0
	Yes, hospitalised	1
	Yes, not hospitalised	2

Specify illness and treatment

.....

p. Anything else (specify)?	No	0
	Yes	1

.....

Q115 Now, considering his/her first degree blood relatives; that is his/her parents, brothers, sisters and children, have any of them had any of the following problems?

IF YES: How many?

- Stroke
- Heart attack
- High BP
- Diabetes
- Cancer
- Leukaemia
- Dementia or problems with memory

(IF YES:) Moved into institution

Nervous complaint or mental illness

**Thank you very much for helping with all these questions, some of which I know may have been upsetting for you.**

Q115. Is there anything else you would like to add, or think it might be helpful for us to know?

Comments

**Observations on relative or carer**

In the opinion of the interviewer, did the relative/carer understand the questions?

- No 0
- Yes 1
- Most 2

Did the relative/carer appear to answer accurately?

- Yes 0
- Mostly 1
- No 2

Did the relative/carer appear to have any cognitive impairment?

- No 0
- Slight 1
- Yes 2

**Time Interview ended:**

**Additional information from the Retrospective Informant Interview**

**Interviewer Ratings**

Project Number:

Is it your impression that there could have been dementia present before death?

- No 0
- Yes 1
- Uncertain 2

If 'Yes' , severity

- Mild 1
- Moderate 2
- Severe 3

Any further information not captured by the interview.....