

**Costs of Family Caregiving (COFAC)  
Questionnaire:**

A questionnaire to explore the financial and emotional costs of caregiving in palliative care

**Carer Questionnaire (to be completed by caregivers with a researcher to assist): Baseline Interview**

*'Carers may or may not be family members, they are lay people in a close supportive role who share in the illness experience of the patient and undertake vital care work and emotional management'*

Participant ID:

Date of completion:

## Section 1: Demographic details

### 1. Gender

Male

Female

### 2. What is your date of birth?

### 3. What is your ethnic group?

White

Mixed/Multiple ethnic groups

Asian/Asian British

Black/ African/Caribbean/Black British

Other ethnic group

### 4. What is your postcode?

### 5. What is the highest level of education that you have completed?

No formal education

Advanced cert/apprenticeship/  
professional qualification

Primary school

Bachelor degree

Secondary school

Masters/Postgrad diploma

Technical or vocational

Doctorate (PhD)

**6. What is your current job, or your last job if not working?**

**7. Does your household own or rent your accommodation?**

Owns with mortgage

Rents

Owns outright

Other e.g. equity release

**8. Do you currently have private health insurance e.g. BUPA, Westfield?**

Yes

No

**9. What was your total household income (before tax) for the past year, including any money from benefits, contributions from parents/children etc?**

Nil

£32,000 to £39,999

£1 to £7,999

£40,000 to £46,999

£8,000 to £15,999

£47,000 or more

£16,000 to £23,999

Don't know

£24,000 to £31,999

Prefer not to answer

**10. How many people are dependent on this income?**

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**11. What is your relationship to [patient name]?**

- |  |  |
|--|--|
| <input type="checkbox"/> He/she is my spouse/partner | <input type="checkbox"/> He/she is my sibling    |
| <input type="checkbox"/> He/she is my son/daughter   | <input type="checkbox"/> He/she is my friend     |
| <input type="checkbox"/> He/she is my parent         | <input type="checkbox"/> Other (please specify): |

**12. What is [patients] gender?**

- Male  Female

**13. What is [patients] date of birth?**

**14. Can you tell me what condition or illness [patient] has been diagnosed with?**

## Section 2: Work-Related Costs

### 15. How would you describe your present status?

- |  |   |
|--|---|
| <input type="checkbox"/> Employed                | <input type="checkbox"/> Self-employed  |
| <input type="checkbox"/> Retired from employment | <input type="checkbox"/> Looking after home/family                              |
| <input type="checkbox"/> Unemployed              | <input type="checkbox"/> Unable to work due to permanent sickness or disability |
| <input type="checkbox"/> Student/pupil           | <input type="checkbox"/> Other (please specify)                                 |

### 16. Has there been any change in your employment status as a result of your caregiving role? E.g. early retirement, resignation, reduction in working hours.

- Yes  No

If yes, what was the change? \_\_\_\_\_

### 17. If employed/self-employed, have you taken any time off work in the last month to care for (patient), including taking them to hospital appointments etc?

- Yes  No  n/a

If yes, how many hours per week on average over the last month

\_\_\_\_\_

If yes, was this time off work:

- Paid  Unpaid  Reduced pay

**18. In the last month, have you lost any pension rights or other benefits (e.g. Working Tax Credits, Job Seekers Allowance) as a result of caregiving?**

Yes

No

Don't know

**If yes,** how much do you estimate this loss to be over the last month?

£ \_\_\_\_\_

## Section 3: Caregiver Time costs

19. Do you live with [patient]?

Yes

No

If no, how much did you spend over the last month on travel to visit [patient]?

Cost of Public Transport	£
Cost of taxis	£
Cost of parking	£
Miles travelled in your own car	Miles:

20. Over the last month, how many hours of care have you provided each week for [patient]?

Type of caregiving	Hours <u>per week</u> , over the last month
Personal care (washing, feeding, moving etc)	
Making appointments and taking to/from appointments	
Household tasks (washing, cleaning, shopping etc)	
Managing finances or other paperwork	
Collecting prescriptions	
Spending time together/with family	
Other	

**21. Over the last month, have any other family members or friends provided care for [patient]?**

Yes       No       Don't know

**If yes,** how many hours of care did they provide each week (over the last month)?

\_\_\_\_\_

Please estimate any costs that they incurred as a result of providing this care (over the last month)?

\_\_\_\_\_

**22. Do you receive any of the following benefits because of your caregiving role?**

Benefit	Do you receive this? yes/no/don't know	Approx. amount <i>per month</i> (£)
Attendance allowance		
Carers allowance		
Carers credit		
Carers premium		
Other		

**If no,** are you are eligible for any of these benefits?

Yes       No       Don't Know

**23. In the last month, have you had to pay someone to look after any other dependants (e.g. children) while you were caring for [patient]?**

Yes       No

**If yes,** how much did you pay in the past month?



## Section 4: Out of Pocket Expenses

24. Over the last month, have you employed any paid carers for [patient]?

Yes

No

If yes, how much was the cost in the last month? \_\_\_\_\_

How much did you pay (if any)? \_\_\_\_\_

25. Over the last month, have you paid for any private healthcare (other than health insurance premiums) for [patient] e.g. private medical consultations, physio, private ambulance?

Yes

No

If yes, how much was the cost in the last month? \_\_\_\_\_

How much did you pay (if any)? \_\_\_\_\_

26. Over the last month, have you paid for any respite care for [patient name] (*respite care is any care to give rest or relief to unpaid carers*)?

Yes

No

If yes, how much did it cost in the last month? \_\_\_\_\_

How much did you pay (if any)? \_\_\_\_\_

27. Over the last month, has [patient] spent any time in care/nursing home?

Yes

No

If yes, how much did it cost in the last month? \_\_\_\_\_

How much did you pay (if any)? \_\_\_\_\_

**28. In the last month, have you paid for any of the following aids, appliances and modifications due to [patients] condition? Please only include items that you have paid for.**

Aid	Description	What was the cost to you?
<b>Walking aids</b> (e.g. stick/crutch, wheelchair, scooter)		
<b>Communications aids</b> (e.g. tablet, lightwriter, phone systems)		
<b>Respiratory Aids</b> (e.g. home oxygen, NIV machine)		
<b>Posture aids</b> (e.g. back support, cushions, chair pad)		
<b>Home living aids</b> (lifting/reclining armchair, stair lift, bath lift, shower seat, raisers for bed)		
<b>Pain relief</b> (e.g. TENS machine)		
<b>Incontinence aids</b> (pads, pants, waterproof sheets/chair covers)		
<b>Feeding aids</b> (bibs, wipes, cups)		
<b>Personal alarms</b> (Lifeline, citywide alarm etc.)		
<b>Additional homeware</b> (clothes, bed linen, towels, new TV etc.)		
<b>Home modifications</b> (ramps, rails, home extensions)		
<b>Car modifications</b> (wheel chair lift, boot hoist)		
<b>Other aids, appliances or modifications?</b>		

**29. In the last month have you spent any money on the following when taking [patient] to appointments at hospital, hospice, GP surgery or elsewhere?**

<b>Cost</b>	<b>Amount spent in the past month/mileage</b>
Transport to appointments at hospital/hospice/ GP surgery  Miles travelled in your own car:  Cost of public transport:  Cost of taxis:  Cost of parking:	
Transport to pharmacy to collect prescriptions  Miles travelled in your own car:  Cost of public transport:  Cost of taxis:  Cost of parking:	
Parking	
Food and drink at hospital, hospice or elsewhere	
Accommodation to be close to hospital, hospice or elsewhere	
Other costs (please specify)	

**30. How much *extra* (if any) have you spent on each of the following items in the last month compared to before [patient name] became ill? If you do not know the actual cost please describe your change in usage.**

	Extra usage/costs in the last month
Telephone/internet charges	
Electricity and heating	
Food and drink	
Cleaners or laundry costs	
Other	

**31. In the last month how much have you spent on prescription charges for [patient]?**

£

**32. In the last month how much have you spent on over the counter medications or therapies for [patient] e.g. paracetamol, indigestion meds?**

£

**33. In the last month how much have you spent on complementary or alternative medicines/therapies for [patient] e.g. homeopathy, acupuncture, Chinese medicines?**

£

## Section 5: Your own health

**34. In the last month, have you incurred any costs relating to health problems of your own that have occurred as a result of your caring role e.g. injuries from lifting?**

Nature of cost e.g. physio for back injury	Cost in the last month

**35. In the last month, have you incurred any costs relating to preventative therapies or respite from caring e.g. osteopath, relaxation massage?**

Nature of cost e.g. osteopath	Cost in the last month

**36. Can you think of ANY other costs that have been incurred over the last month as a consequence of [patients] illness? E.g. legal costs**

What are the costs?	How much was the cost?	Who paid?