Appendix 5b: Questionnaire

THE DEBENHAM PROJECT
Dementia - Caring for the Carers
A Dementia Friendly Community

Carer Well-Being & Support

A questionnaire for carers of people with dementia

Before we start filling in this questionnaire with you, there are a few things you should know.

- This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carer' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.

- It can be filled in by anyone who has a role in caring for someone with dementia. You don't have to be a person's main carer or live at the same address as them.

- There are no wrong or right answers. Just provide whatever information you can to help us help you.

- The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so in the section about your needs, on page

A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write today's date: _____

Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
1. not having enough time to yourself?	☐	☐	☐	☐
2. having to put the needs of the person you care for ahead of your own needs?	☐	☐	☐	☐
3. not being able to take a break from caring?	☐	☐	☐	☐
4. not being able to plan for the future?	☐	☐	☐	☐
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	☐	☐	☐	☐

Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
6. strains in your relationship with the person you care for?	☐	☐	☐	☐
7. the person you care for being too dependent on you at the moment?	☐	☐	☐	☐
8. the person you care for becoming too dependent on you in the future?	☐	☐	☐	☐
9. the person you care for saying things that upset you?	☐	☐	☐	☐
10. feeling irritable with the person you care for?	☐	☐	☐	☐

11. reaching "breaking point", where you feel you can't carry on with things as they are?	☐	☐	☐	☐

Your relationships with family and friends (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	☐	☐	☐	☐
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	☐	☐	☐	☐
14. feeling isolated and lonely because of the situation you are in?	☐	☐	☐	☐
15. not getting the support you need from family and friends?	☐	☐	☐	☐

Your financial situation (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
16. your own financial situation?	☐	☐	☐	☐
17. the financial situation of the person you care for?	☐	☐	☐	☐
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	☐	☐	☐	☐

Your physical health (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
19. your own physical health?	☐	☐	☐	☐
20. your caring role making your physical health worse?	☐	☐	☐	☐

Your emotional well-being (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	☐	☐	☐	☐
22. feeling depressed?	☐	☐	☐	☐
23. being unable to see anything positive in your life?	☐	☐	☐	☐
24. lack of sleep brought about through worry or stress?	☐	☐	☐	☐
25. lack of sleep caused by the person you care for keeping you awake at night?	☐	☐	☐	☐

26. feeling so exhausted that you can't function properly?	☐	☐	☐	☐

Stigma and discrimination

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	☐	☐	☐	☐

Your own safety

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	☐	☐	☐	☐
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	☐	☐	☐	☐

The safety of the person you care for

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	A little	Not at all
30. harming themselves?	☐	☐	☐	☐
31. getting themselves into dangerous situations?	☐	☐	☐	☐
32. relapsing or deteriorating, such that it puts their safety at risk?	☐	☐	☐	☐

B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

In general, **how satisfied** are you…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	☐	☐	☐	☐
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	☐	☐	☐	☐
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	☐	☐	☐	☐
4. with how easy it is to understand the information you have?	☐	☐	☐	☐
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	☐	☐	☐	☐
6. that you are clear about who to go to for the information and advice you need?	☐	☐	☐	☐
7. that you are clear about who to contact if there is an emergency and you need help right away?	☐	☐	☐	☐
8. that you are clear about who to call if you have a routine inquiry?	☐	☐	☐	☐

Your involvement in treatment and care planning

(Please tick one box on each line.)

In general, **how satisfied** are you with…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	☐	☐	☐	☐

10. your ability to influence important decisions?	☐	☐	☐	☐

Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, **how satisfied** are you with…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
11. how easy it is to get help and support from staff for the *person you care for* (e.g. to prevent relapse)?	☐	☐	☐	☐
12. how easy it is to get help and support from staff for *yourself* (e.g. advice on how to deal with certain behaviours)	☐	☐	☐	☐
13. the quality of help and support from staff for the *person you care for*?	☐	☐	☐	☐
14. your relationships with key staff who support the *person you care for?*	☐	☐	☐	☐
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	☐	☐	☐	☐
16. how seriously staff take what you say to them?	☐	☐	☐	☐
17. the level of understanding staff have of what it must be like to be in your situation?	☐	☐	☐	☐

C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

1. Which of the following types of support, if any, do you use to allow you to take a break from caring?

	Not at all	Occasionally	In emergencies or I need a break	Regularly
Friends/family providing care				
Paid carers coming into the home				
Paid carers providing care away from the home (e.g. care home)				
Supported activities out of the home, for the person you care for				
Supported breaks for you and the person you care for, away from the home				

Other respite care				

2. If you do not have any types of support, why might this be the case?

	I need help but I don't know where or how to get it	I would like some help on an ad hoc basis but don't know how to arrange this	I can manage at the moment	I don't need help at this stage

3. Would you like more support to help you in your role as a carer?

No, not at all ☐

Yes, a little ☐

Yes, a lot ☐

4. What types of additional support would you most like to receive?

5. Is there anything else that's important to your well-being that you'd like help with or would like to change?

D. The needs of the cared for person

About the Person or Persons You Care For

This next section asks about the person you care for with dementia. There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

1. Who do you care for?

a) My **son/daughter**

b) My **partner/spouse**

c) My **brother/sister**

d) My **parent**

e) My **friend**

2. Which of the following statements best describes your role as a carer at the moment?

a) I am the **only** care giver

b) I **share** caring responsibilities with others, but I am the **main** caregiver

c) I **share** caring responsibility with others

d) I share caring responsibilities but **someone else is the main** caregiver

e) Other (please explain)