SPIRiTT Unique Identification Number: Assessment time-point

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Background questionnaire for Live-in carer of person with Parkinson's

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: __/___/ 20__ **Time:** __:__ AM PM **Location:** ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

ABOUT YOUR CARING ROLE

In answering the questions below, please place ticks √ in the relevant boxes.

1) On A TYPICAL DAY, how much of the time can you leave the person with Parkinson's at home alone?

☐ Less than 25% of the time ☐ Between 25 to 49% of the time ☐ Between 50 to 74% of the time ☐ Between 75 to 100% of the time

2) In AN AVERAGE WEEK, how many of hours of care or assistance do you provide to the person with Parkinson's?

_____ hours per week

3) What sort of activities do you do? *(Please tick all that applies)*

☐ Communicate/leave reminders	☐ Attending to person's appearance (e.g. help with grooming)	☐ Help with dressing/ undressing etc	☐ Household chores (e.g. minor repairs/ gardening)
☐ Managing money	☐ Cooking/preparing meals/eating	☐ Transport/take out shopping/outings etc	☐ Supervising the person
☐ Shopping	☐ Other (please specify): _____	☐ Other (please specify): _____	☐ Other (please specify): _____

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4) **Other than you, does anyone else (such as friends, relatives, paid carers) provide regular care for the person with Parkinson's?**

☐ Yes, unpaid carer (such as friends or relatives) ☐ Yes, paid carer ☐ No ☐ Other (please specify): _____

5) **Have you given up or cut down on work in order to provide care for the person with Parkinson's?**

☐ Yes, cut down on work ☐ Yes, given up work ☐ No

6) **Do you frequently feel sad or depressed?** ☐ Yes ☐ No

ABOUT YOU AND YOUR HEALTH

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

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MODIFIED CAREGIVER STRAIN INDEX (CSI)

Here is a list of things that other caregivers have found to be difficult. Please place a checkmark/tick √ in the box that applies to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis	Yes, sometimes	No
1) **My sleep is disturbed** *(for example: the person I care for is in and out of bed or wanders around at night)*	☐	☐	☐
2) **Caregiving is inconvenient** *(For example: helping takes so much time or it's a long drive over to help)*	☐	☐	☐
3) **Caregiving is a physical strain** *(For example: lifting in or out of a chair; effort or concentration is required)*	☐	☐	☐
4) **Caregiving is confining** *(For example: helping restricts free time or I cannot go visiting)*	☐	☐	☐
5) **There have been family adjustments** *(For example: helping has disrupted my routine; there is no privacy)*	☐	☐	☐
6) **There have been changes in personal plans** *(For example: I had to turn down a job; I could not go on vacation)*	☐	☐	☐
7) **There have been other demands on my time** *(For example: other family members need me)*	☐	☐	☐
8) **There have been emotional adjustments** *(For example: severe arguments about caregiving)*	☐	☐	☐
9) **Some behaviour is upsetting** *(For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)*	☐	☐	☐
10) **It is upsetting to find the person I care for has changed so much from his/her former self** *(For example: s/he is a different person that s/he used to be)*	☐	☐	☐
11) **There have been work adjustments** *(For example: I have to take time off for caregiving duties)*	☐	☐	☐
12) **Caregiving is a financial strain**	☐	☐	☐
13) **I feel completely overwhelmed** *(For example: I worry about the person I care for; I have concerns about how I will manage)*	☐	☐	☐

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EuroQol QUESTIONNAIRE

Please indicate which statement best describes your own health. Please tick only one box in each section.

1) Mobility
- ☐ I have no problems with walking around
- ☐ I have some problems with walking around
- ☐ I am confined to bed

2) Self-care
- ☐ I have no problems with self-care
- ☐ I have some problems with washing or dressing myself
- ☐ I am unable to wash or dress myself

3) Usual activities (e.g. work, study, housework, family or leisure activities)
- ☐ I have no problems with performing my usual activities
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

4) Pain/Discomfort
- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

5) Anxiety/Depression
- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

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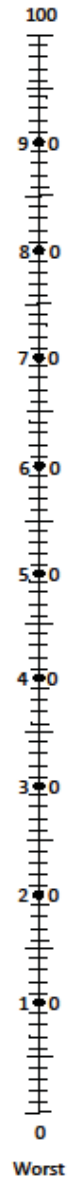
EuroQoL THERMOMETER

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is TODAY, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is TODAY.



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GENERAL HEALTH QUESTIONNAIRE – 12

Please consider THE LAST FOUR WEEKS and answer the following questions by placing a checkmark/tick in one of the boxes.

In the LAST 4 WEEKS, have you:	much less than usual	less than usual	better than usual	same as usual
1) been able to concentrate on what you're doing?				
2) felt you were playing a useful part in things?				
3) felt capable of making decisions about things?				
4) been able to enjoy your normal day-to-day activities?				
5) been able to face up to your problems?				
6) been feeling reasonably happy, all things considered?				

In the LAST 4 WEEKS, have you:	not at all	no more than usual	rather more than usual	much more than usual
7) lost much sleep over worry?				
8) felt constantly under strain?				
9) felt you couldn't overcome your difficulties?				
10) been feeling unhappy and depressed?				
11) been losing confidence in yourself?				
12) been thinking of yourself as a worthless person?				

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FRENCHAY ACTIVITIES INDEX

Please answer the following questions by placing a checkmark/tick in one of the boxes.

In the LAST 3 MONTHS, how often have you undertaken:	**Never**	**Less than once a week**	**1 to 2 times a week**	**Most days**
1) preparing main meals? *(not just making snacks or reheating prepared food)*				
2) washing up? *(not just rinsing or an occasional item)*				

In the LAST 3 MONTHS, how often have you undertaken:	**Never**	**1 to 2 times in 3 months**	**3 to 12 times in 3 months**	**At least weekly**
3) washing clothes?				
4) light housework? *(such as dusting, polishing, ironing)*				
5) heavy housework? *(such as changing beds, cleaning floors, vacuuming, moving chairs, gardening)*				
6) local shopping?				
7) social outings? *(can include social activities at home such as visits from friends, not for the purpose of providing care)*				
8) walking outside more than 15 minutes? *(includes shopping)*				
9) actively pursuing a hobby *(includes reading)*?				
10) driving a car/going on a bus? *(must travel independently)*				

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WELLBEING QUESTIONNAIRE (Hospital Anxiety and Depression Scale)

Without thinking too much, please place a checkmark/tick √ in the box that applies to you. Please choose only one box for each question.

1) I feel tense or 'wound up'

☐ Not at all ☐ From time to time, occasionally ☐ A lot of the time ☐ Most of the time

2) I still enjoy the things I used to enjoy

☐ Hardly at all ☐ Only a little ☐ Not quite so much ☐ Definitely as much

3) I get a sort of frightened feeling as if something awful is about to happen

☐ Not at all ☐ A little, but it does not worry me ☐ Yes, but not too badly ☐ Very definitely and quite badly

4) I can laugh and see the funny side of things

☐ Not at all ☐ Definitely not so much now ☐ Not quite so much now ☐ As much as I always could

5) Worrying thoughts go through my mind

☐ Only occasionally ☐ From time to time, but not too often ☐ A lot of the time ☐ A great deal of the time

6) I feel cheerful

☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

7) I can sit at ease and feel relaxed

☐ Not at all ☐ Not often ☐ Usually ☐ Definitely

8) I feel as if I am slowed down

☐ Not at all ☐ Sometimes ☐ Very often ☐ Nearly all the time

9) I get a sort of frightened feeling like 'butterflies' in the stomach

☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

10) I have lost interest in my appearance

☐ Definitely ☐ I do not take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever

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11) I feel restless as if I have to be on the move

☐ Not at all ☐ Not very much ☐ Quite a lot ☐ Very much indeed

12) I look forward with enjoyment to things

☐ Hardly at all ☐ Definitely less than I used to ☐ Rather less than I used to ☐ As much as I ever did

13) I get sudden feelings of panic

☐ Not at all ☐ Not very often ☐ Quite often ☐ Very often indeed

14) I can enjoy a good book or radio or TV programme

☐ Very seldom ☐ Not often ☐ Sometimes ☐ Often

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SHORT FORM 36 HEALTH SURVEY

Please respond to the questions below, by placing a checkmark/tick √ in the appropriate box.

1) In general, would you say your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2) Compared to one year ago, how would you rate your health in general NOW?

☐ Much better now than one year ago ☐ Somewhat better now than one year ago ☐ About the same as one year ago ☐ Somewhat worse than one year ago ☐ Much worse than one year ago

With reference to the activities listed below that you may do during a typical day, does your health NOW limit you in these activities? If so, how much?	No, not limited at all	Yes, limited a little	Yes, limited a lot
3) Vigorous activities such as running, lifting heavy objects, participating in strenuous sports			
4) Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
5) Lifting or carrying groceries			
6) Climbing several flights of stairs			
7) Climbing one flight of stairs			
8) Bending, kneeling or stooping			
9) Walking more than a mile			
10) Walking half a mile			
11) Walking one hundred yards			
12) Bathing or dressing yourself			

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?	Yes	No
13) Cut down on the amount of time you spent on work or other activities		
14) Accomplished less than you would like		
15) Were limited in the kind of work or other activities		
16) Had difficulty performing the work or other activities (for example, it took extra effort)		

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 any EMOTIONAL problems (such as feeling depressed or anxious)?	Yes	No
17) Cut down on the amount of time you spent on work or other activities		
18) Accomplished less than you would like		
19) Did not do work or other activities as carefully as usual		

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20) During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

21) How much bodily pain have you had during the PAST 4 WEEKS?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

22) During the PAST 4 WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

23) During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

How much of the time during the PAST 4 WEEKS:	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
24) Did you feel full of life?						
25) Have you been a very nervous person?						
26) Have you felt so down in the dumps that nothing could cheer you up?						
27) Have you felt calm and peaceful?						
28) Did you have a lot of energy?						
29) Have you felt downhearted and low?						
30) Did you feel worn out?						
31) Have you been a happy person?						
32) Did you feel tired?						

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How TRUE or FALSE is each of the following statements to you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33) I seem to get ill more easily than other people					
34) I am as healthy as anybody I know					
35) I expect my health to get worse					
36) My health is excellent					

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ACTIVITIES OF DAILY LIVING QUESTIONNAIRE (BARTHEL)

Please select the statement which best describes your situation. Please tick only one box in each section.

1) Mobility around house

☐ Immobile ☐ Wheelchair independent around corners etc ☐ Walks with verbal or physical help of 1 person ☐ Independent *(but can use walking aid such as a stick)*

2) Stairs

☐ Unable ☐ Needs verbal or physical help *(carrying aid)* ☐ Independent up and down

3) Transfer from bed to chair and back

☐ Unable ☐ Needs major help (1 or 2 people, physical help) ☐ Needs minor verbal or physical help ☐ Independent

4) Bathing

☐ Dependent ☐ Independent

5) Grooming (personal hygiene such as brushing teeth and hair, shaving, washing face)

☐ Needs help ☐ Independent

6) Dressing

☐ Dependent ☐ Needs help but can do half unaided ☐ Independent

7) Feeding (able to eat normal food, not just soft food)

☐ Unable ☐ Needs help cutting, spreading butter etc ☐ Independent

8) Toilet use

☐ Dependent ☐ Needs some help but can do something ☐ Independent

9) Bladder

☐ Incontinent or catheterised and unable to manage ☐ Occasional accident (maximum 1 time in a day) ☐ Continent over 7 days

10) Bowels

☐ Incontinent ☐ Occasional accident (1 per week) ☐ Continent

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THANK YOU for taking the time to complete this questionnaire.

Please check through to ensure that you have answered all of the questions.

Your input is extremely valued and very much appreciated.

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