P | | | / | | |

COMMEND RCT

Participant booklet

Baseline

Date of completion

d	d	m	m	y	y	y	y

Method of completion

- ☐ Booklet returned by post
- ☐ Booklet completed with participant by phone
- ☐ Booklet completed with participant by video conference
- ☐ Booklet completed with participant by email
- ☐ Booklet completed with participant at face-to-face visit

COMMEND RCT

McGill Quality of Life Questionnaire - Revised©

Baseline

P ☐☐/☐☐☐

Instructions

This questionnaire contains statements that are each followed by two opposite answers.

Numbers extend from one extreme answer to the opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

START

Please answer for how you have been feeling *JUST IN THE PAST TWO (2) DAYS*

Part A - Overall Quality of Life

A. Considering all parts of my life (for example, physical, emotional, social, spiritual, and financial) over the past two days (48 hours) the quality of my life was:

very bad	0	1	2	3	4	5	6	7	8	9	10	excellent

Continue to Part B

Cohen SR et al, Palliat Med.,2017 Feb;31(2):120-129

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McGill Quality of Life Questionnaire - Revised©

Baseline

P ☐☐/☐☐☐

Part B Physical

1. Over the past two days (48 hours) my physical symptoms (such as pain, nausea, tiredness and others) were:*

not a problem	0	1	2	3	4	5	6	7	8	9	10	a tremendous problem

**If, over the past two days, you had no physical symptoms or problems, please circle '0 – not a problem' and go to statement #2.*

Please list the physical symptoms that were a problem (please write clearly).

2. Over the past two days (48 hours) I felt:

physically terrible	0	1	2	3	4	5	6	7	8	9	10	physically well

3. Over the past two days (48 hours), being physically unable to do things I wanted was:

not a problem	0	1	2	3	4	5	6	7	8	9	10	a tremendous problem

Continue to Part C

Cohen SR et al, Palliat Med.,2017 Feb;31(2):120-129

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McGill Quality of Life Questionnaire - Revised©

Baseline

P ☐☐/☐☐☐

Part C Feelings and thoughts

4. Over the past two days (48 hours), I was depressed:

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely

5. Over the past two days (48 hours), I was nervous or worried:

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely

6. Over the past two days (48 hours), I felt sad:

never	0	1	2	3	4	5	6	7	8	9	10	always

7. Over the past two days (48 hours), when I thought of the future, I was:

not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified

8. Over the past two days (48 hours), my life was:

utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful

9. When I think about my whole life, I feel that in achieving life goals I have:

made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfilment

10. Over the past two days (48 hours), I felt that the amount of control I had over my life was:

not a problem	0	1	2	3	4	5	6	7	8	9	10	a tremendous problem

11. Over the past two days (48 hours), I felt good about myself as a person

completely disagree	0	1	2	3	4	5	6	7	8	9	10	completely agree

Continue to Part D

Cohen SR et al, Palliat Med.,2017 Feb;31(2):120-129

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McGill Quality of Life Questionnaire - Revised©

Baseline

P ☐☐/☐☐☐

Part D Social

12. Over the past two days (48 hours), communication with the people I care about was:

difficult	0	1	2	3	4	5	6	7	8	9	10	very easy

13. Over the past two days (48 hours), I felt my relationships with the people I care about were:

more distant than I would like	0	1	2	3	4	5	6	7	8	9	10	very close

14. Over the past two days (48 hours), I felt supported:

not at all	0	1	2	3	4	5	6	7	8	9	10	completely

Cohen SR et al, Palliat Med.,2017 Feb;31(2):120-129

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COMMEND RCT

HADS

Baseline

P ☐☐/☐☐☐

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate is best.

I feel tense or 'wound up'	
Most of the time	☐
A lot of the time	☐
From time to time, occasionally	☐
Not at all	☐

I feel as if I am slowed down	
Nearly all of the time	☐
Very often	☐
Sometimes	☐
Not at all	☐

I still enjoy the things I used to enjoy:	
Definitely as much	☐
Not quite so much	☐
Only a little	☐
Hardly at all	☐

I get a sort of frightened feeling like 'butterflies' in the stomach	
Not at all	☐
Occasionally	☐
Quite often	☐
Very often	☐

I get a sort of frightened feeling as if something awful is about to happen	
Very definitely and quite badly	☐
Yes, but not too badly	☐
A little, but it doesn't worry me	☐
Not at all	☐

I have lost interest in my appearance	
Definitely	☐
I don't take as much care as I should	☐
I may not take quite as much care	☐
I take just as much care as ever	☐

I can laugh and see the funny side of things	
As much as I always could	☐
Not quite so much now	☐
Definitely not so much now	☐
Not at all	☐

I feel restless as if I have to be on the move	
Very much indeed	☐
Quite a lot	☐
Not very much	☐
Not at all	☐

Zigmond, AS; Snaith, RP (1983). "The hospital anxiety and depression scale". *Acta Psychiatrica Scandinavica*. 67 (6): 361–370

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COMMEND RCT

HADS

Baseline

P ☐☐/☐☐☐

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate is best.

Worrying thoughts go through my mind	
A great deal of the time	☐
A lot of the time	☐
From time to time, but not too often	☐
Only occasionally	☐

I look forward with enjoyment to things	
As much as I ever did	☐
Rather less than I used to	☐
Definitely less than I used to	☐
Hardly at all	☐

I feel cheerful	
Not at all	☐
Not often	☐
Sometimes	☐
Most of the time	☐

I get sudden feelings of panic	
Very often indeed	☐
Quite often	☐
Not very often	☐
Not at all	☐

I can sit at ease and feel relaxed	
Definitely	☐
Usually	☐
Not often	☐
Not at all	☐

I can enjoy a good book or radio or TV program	
Often	☐
Sometimes	☐
Not often	☐
Very seldom	☐

Zigmond, AS; Snaith, RP (1983). "The hospital anxiety and depression scale".
Acta Psychiatrica Scandinavica. 67 (6): 361–370

COMMEND RCT

Self-Administered ALS-FRS-Revised

Baseline

P ☐☐/☐☐☐

The following questions refer to how you are currently functioning at home.

Please read each item carefully and base your answers on your functioning today compared to the time before you had any symptoms of MND.

Please choose the answer that best fits your functional status today.

Place an "x" in the box next to your answer.

Compared to the time before you had symptoms of MND:

1. Have you noticed any changes in your **speech**?

   ☐ **no change**

   ☐ **noticeable speech differences**

   ☐ speech has changed; **asked often to repeat words or phrases**

   ☐ speech has changed; sometimes need the use of **alternative communication methods** (i.e. computer, writing pad, letter board or eye chart)

   ☐ **unable** to communicate verbally

---

2. Have you noticed any changes (increases) in the amount of **saliva** in your mouth (regardless of any medication use)?

   ☐ **no change**

   ☐ slight but definite excess of saliva with or without **night time drooling**

   ☐ moderate amounts of excessive saliva with or without **minimal day time drooling**

   ☐ marked amounts of excessive saliva with **some day time drooling**

   ☐ marked excessive saliva with **marked drooling** requiring a constant tissue or handkerchief

---

3. Have there been any changes in your ability to **swallow**?

   ☐ **no changes** (all foods and liquids)

   ☐ some changes in swallowing or **occasional choking episodes** (including coughing during swallowing)

   ☐ unable to eat all consistencies of food and have **modified the consistency of foods** eaten

   ☐ use a **feeding tube (PEG) to supplement** what is eaten by mouth

   ☐ **do not eat anything by mouth** and receive all nutrition through a feeding tube (PEG)

Self-Administered ALS-FRS-Revised

Baseline

P ☐☐/☐☐☐

Compared to the time before you had symptoms of MND:

4. Has your **handwriting** changed? Please choose the answer that describes your handwriting with your **dominant (usual)** hand without a cuff or brace.

- ☐ **no changes**
- ☐ slower and/or sloppier but all the words are **legible**
- ☐ **not all words are legible**
- ☐ able to **hold a pen** but **unable to write**
- ☐ **unable to hold a pen**

The following question refers to your ability to **cut foods and handle utensils** (feed yourself) compared to before you had symptoms of MND.

If most of your nutrition is through a feeding tube (PEG), skip to **part b** of this question. If you eat most of your meals by mouth answer **part a**.

5**a**. **Cutting food and handling utensils:**

- ☐ **no change**
- ☐ **somewhat slow and clumsy** (or different than before) but no assistance or adaptive equipment
- ☐ **sometimes need help** with cutting more difficult foods
- ☐ **food must be cut by someone else** but can feed slowly without assistance
- ☐ **need to be fed**

5**b**. Using a **feeding tube** (PEG)

- ☐ use PEG **without assistance or difficulty**
- ☐ use PEG without assistance however may be **slow and/or clumsy**
- ☐ **require assistance with closures and fasteners**
- ☐ **provide minimal assistance to caregiver**
- ☐ **unable to perform** any of the manipulations

COMMEND RCT

Self-Administered ALS-FRS-Revised

Baseline

P ☐☐/☐☐☐

Compared to the time before you had symptoms of MND:

6. Has your ability to **dress and perform self-care activities** (i.e. bathing, teeth brushing, shaving, combing your hair, other hygienic activities) changed?

- ☐ **no change**
- ☐ perform self-care activities without assistance but **with increased effort or decreased efficiency**
- ☐ require **intermittent assistance or use different methods** (i.e. sit down to get dressed, fasten buttons with a fastener or your non-dominant hand)
- ☐ **require daily assistance**
- ☐ do not perform self-care activities and **completely dependent** on caregiver

---

7. Has your ability to **turn in bed and adjust the bedclothes** (i.e. cover yourself with a sheet or blanket) changed?

- ☐ **no change**
- ☐ can turn in bed and adjust the bed clothes **without assistance** but it is **slower or more clumsy**
- ☐ can turn in bed **or** adjust the bedclothes **without assistance but with great difficulty**
- ☐ can **initiate** turning in bed or adjusting the bed clothes but **require assistance** to complete the task
- ☐ **helpless** in bed

---

8. Has your ability to **walk** changed?

- ☐ **no change**
- ☐ **walking has changed** but **do not require any assistance or devices** (i.e. foot brace, cane, walker)
- ☐ **require assistance** to walk (i.e. cane, walker, foot brace or hand held assistance)
- ☐ **can move legs or stand up** but **unable to walk** from room to room
- ☐ **cannot walk** or move my legs

---

9. Has your ability to **climb stairs** changed?

- ☐ **no change**
- ☐ **slower**
- ☐ **unsteady** and/or more **fatigued**
- ☐ **require assistance** (i.e. using the handrail, cane or person)
- ☐ **cannot** climb stairs

Compared to the time before you had symptoms of MND:

10. Do you experience **shortness of breath** or have **difficulty breathing**?

- ☐ **no change**
- ☐ shortness of breath only **with walking**
- ☐ shortness of breath with **minimal exertion** (i.e. talking, eating, bathing or dressing)
- ☐ shortness of breath **at rest** while either sitting or lying down
- ☐ **significant shortness of breath** (all of the time) and considering using mechanical ventilation

---

11. Do you experience shortness of breath or have difficulty breathing while lying down on your back?

- ☐ **no change**
- ☐ occasional shortness of breath while lying on back but **don't routinely use more than two (2) pillows** to sleep
- ☐ shortness of breath while lying on back and **require more than two pillows** (or an equivalent) **to sleep**
- ☐ **can only sleep sitting up** due to shortness of breath
- ☐ **require the use of respiratory (breathing) support** (BiPAP® or invasive ventilation via tracheostomy) to sleep and **do not sleep without it**

---

12. Do you require **respiratory (breathing) support**?

- ☐ **no respiratory support**
- ☐ **intermittent use of BiPAP®**
- ☐ continuous use of **BiPAP® at night**
- ☐ continuous use of **BiPAP® at night and during the day** (nearly 24 hours per day)
- ☐ **mechanical ventilation** by intubation or tracheostomy

(BiPAP® is commonly used to describe non-invasive positive pressure ventilation and its use here in no way endorses or promotes a particular product)

COMMEND RCT

EQ5D-5L

Baseline

P ☐☐/☐☐☐

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

- I have no problems in walking about ☐
- I have slight problems in walking about ☐
- I have moderate problems in walking about ☐
- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE

- I have no problems washing or dressing myself ☐
- I have slight problems washing or dressing myself ☐
- I have moderate problems washing or dressing myself ☐
- I have severe problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ☐
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ☐
- I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

- I am not anxious or depressed ☐
- I am slightly anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am severely anxious or depressed ☐
- I am extremely anxious or depressed ☐

COMMEND RCT

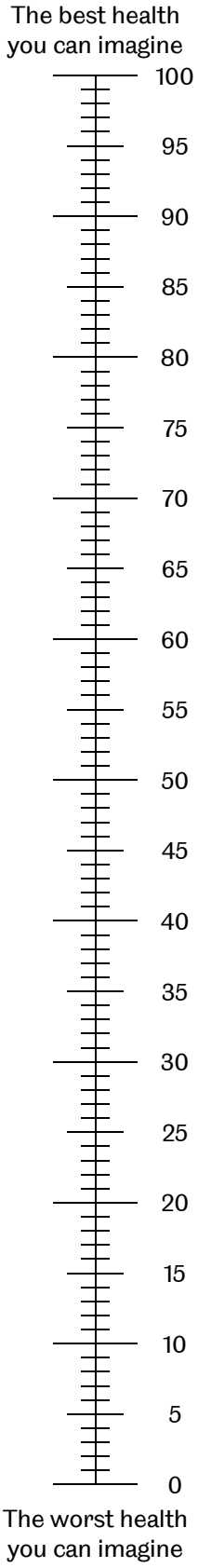
P ☐☐/☐☐☐

EQ5D-5L

Baseline

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



COMMEND RCT

Acceptance and Action Questionnaire - II

Baseline

P ☐☐/☐☐☐

Below you will find a list of statements.

Please rate how true each statement is for you by circling a number next to it.

Use the scale below to make your choice.

1	*2*	*3*	*4*	*5*	*6*	*7*
never true	*very seldom true*	*seldom true*	*sometimes true*	*frequently true*	*almost always true*	*always true*

		Never true	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1.	My painful experiences and memories make it difficult for me to live a life that I would value	1	2	3	4	5	6	7
2.	I'm afraid of my feelings	1	2	3	4	5	6	7
3.	I worry about not being able to control my worries and feelings	1	2	3	4	5	6	7
4.	My painful memories prevent me from having a fulfilling life	1	2	3	4	5	6	7
5.	Emotions cause problems in my life	1	2	3	4	5	6	7
6.	It seems like most people are handling their lives better than I am	1	2	3	4	5	6	7
7.	Worries get in the way of my success	1	2	3	4	5	6	7

Bond, F. W., S. C. Hayes, et al. (2011). "Preliminary psychometric properties of the Acceptance and Action Questionnaire–II: A revised measure of psychological inflexibility and experiential avoidance." Behavior Therapy 42(4): 676-688.

COMMEND RCT

Adapted CSRI

P ☐☐/☐☐☐

Baseline

Primary & community services

Have you used any of the following in the last **6** months? ☐ Yes ☐ No

(✓)	Service (please tick all that apply)	Number of visits	Average duration	Additional information (if any)
	For example, if you saw your GP three (3) times in the last 6 months and most visits were about 10 minutes long, complete as follows:			
☑	GP	0 3	1 0 mins	
☐	GP	☐☐	☐☐ mins	
☐	Physiotherapist	☐☐	☐☐ mins	
☐	Occupational therapist	☐☐	☐☐ mins	
☐	Speech & Language therapist	☐☐	☐☐ mins	
☐	Dietician	☐☐	☐☐ mins	
☐	Nutrition nurse	☐☐	☐☐ mins	
☐	Social worker	☐☐	☐☐ mins	
☐	MNDA advisor	☐☐	☐☐ mins	
☐	MNDA volunteer visitor	☐☐	☐☐ mins	
☐	Psychologist / psychotherapist	☐☐	☐☐ mins	
☐	Community mental health team	☐☐	☐☐ mins	
☐	Home help (household tasks)	☐☐	☐☐ mins	
☐	Home help (personal care)	☐☐	☐☐ mins	
☐	Palliative care nurse	☐☐	☐☐ mins	
☐	MND nurse specialist	☐☐	☐☐ mins	
☐	Respiratory nurse specialist	☐☐	☐☐ mins	
☐	District nurse	☐☐	☐☐ mins	
☐	Sitting service (charity provision)	☐☐	☐☐ mins	
☐	Counselling	☐☐	☐☐ mins	
☐	Alternative therapist (e.g. homeopath)	☐☐	☐☐ mins	
☐	Other, please specify:	☐☐	☐☐ mins	
☐	Other, please specify:	☐☐	☐☐ mins	
☐	Other, please specify:	☐☐	☐☐ mins	

COMMEND RCT

Adapted CSRI

Baseline

P ☐☐/☐☐☐

Hospital, nursing home, or hospice inpatient services

Have you used any of the following in the last **6** months? ☐ Yes ☐ No

(✓)	Service (please tick all that apply)	Number of visits	Total nights	Additional information (if any)
	For example, if you used a hospice for respite two (2) times in the last 6 months and you stayed for 2 nights for the first time and 3 for the second, complete as follows			
☑	Hospice (including for respite care)	02	05	
☐	Nursing or residential home			
☐	Hospice (including for respite care)			
☐	Neurology inpatient ward			
☐	Intensive care unit			
☐	Admission for gastrostomy tube insertion / management			
☐	Admission for NIV / IV assessment / management			
☐	Other inpatient ward, specify type of ward:			
☐	Other inpatient ward, specify type:			

Outpatient and day care services

Have you attended any of the following in the last **6** months? ☐ Yes ☐ No

(✓)	Service (please tick all that apply)	Number of attendances	Average duration	Additional information (if any)
☐	Neurology outpatient ward	☐☐ in last 6 months	☐☐☐ mins	
☐	Other hospital outpatient visit, specify:	☐☐ in last 6 months	☐☐☐ mins	
☐	Day care centre (nursing home)	☐☐ in last 6 months	☐☐☐ mins	
☐	Day care centre (hospice)	☐☐ in last 6 months	☐☐☐ mins	
☐	A&E visit (**without** admission)	☐☐ in last 6 months	☐☐☐ mins	

COMMEND RCT

Adapted CSRI

Baseline

P ☐☐/☐☐☐

Equipment

Have you obtained (bought, been supplied with, or been loaned) any of the following equipment in the last **6** months because of your ALS / PMA / PLS? ☐ Yes ☐ No

(✓)	Service (please tick all that apply)	Provider (if more than one provider, please tick all that apply)					
☐	Ankle / foot orthotic	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Walking aid – cane	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Walking aid – zimmer / rollator	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Wheelchair - manual	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Wheelchair - electric	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Adapted car with wheelchair access	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Mobile arm support	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Lightwriter	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Speech amplifier	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Stairlift	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Specialist cutlery / cups / plates	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Riser recliner chair	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Specialist bed	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Mattress elevator	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Hoist – bedroom / mobile	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Wash and dry toilet	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Bath hoist	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Neck support	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Specialist computer equipment	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Environmental controls / switch	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Feeding pump (gastrostomy)	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Breathing equipment (NIV)	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	
☐	Other, please specify:	☐ NHS	☐ LA	☐ Charity	☐ Self	☐ Other:	

Home adaptations

Have any of the following adaptations been made to your home in the last **6** months because of your ALS / PMA / PLS?

☐ Yes ☐ No

(✓)	**Service** (please tick all that apply)	**Provider** (if more than one provider, please tick all that apply)
☐	Extension built	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Downstairs toilet installed	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Downstairs shower installed	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Wheelchair ramps installed	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Doors widened	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Bathroom adapted	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Through floor lift / elevator	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Hand rails installed	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:
☐	Other, please specify:	☐ NHS ☐ LA ☐ Charity ☐ Self ☐ Other:

Continued on the next page

COMMEND RCT

Adapted CSRI

Baseline

P ☐☐/☐☐☐

Psychological therapies

Have you accessed any of the following psychological therapies from external sources (i.e. not as part of the trial) in the last **6** months? ☐ Yes ☐ No

(✓)	Therapy (please tick all that apply)	Number of attendances	Average duration	Provider
☐	CBT (Cognitive Behavioural Therapy) (A talking therapy with an emphasis on changing thoughts by looking at the evidence for and against them, and an emphasis on changing behaviours.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Relaxation therapy (A talking therapy with an emphasis on learning deep breathing or muscle relaxation skills.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Mindfulness-Based Cognitive Therapy or Mindfulness-based Stress Reduction (A talking therapy with an emphasis on observing thoughts and feelings and allowing them to be rather than trying to change them.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Counselling (A talking therapy with a focus on the client doing most of the talking, with little skills practice in session and at home.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Psychodynamic therapy (A talking therapy focussed on the past, on the subconscious, and on repeating patterns in relationships.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Behavioural activation (A talking therapy aimed at helping to increase activities that give a sense of pleasure or mastery / achievement in one's life.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Systemic therapy (A talking therapy aimed at helping families or couples to explore difficulties they are experiencing.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Not sure of therapy type (Received a form of talking therapy but not sure what type.)	☐☐	☐☐☐ mins	☐ NHS ☐ Private
☐	Other, please state / describe	☐☐	☐☐☐ mins	☐ NHS ☐ Private

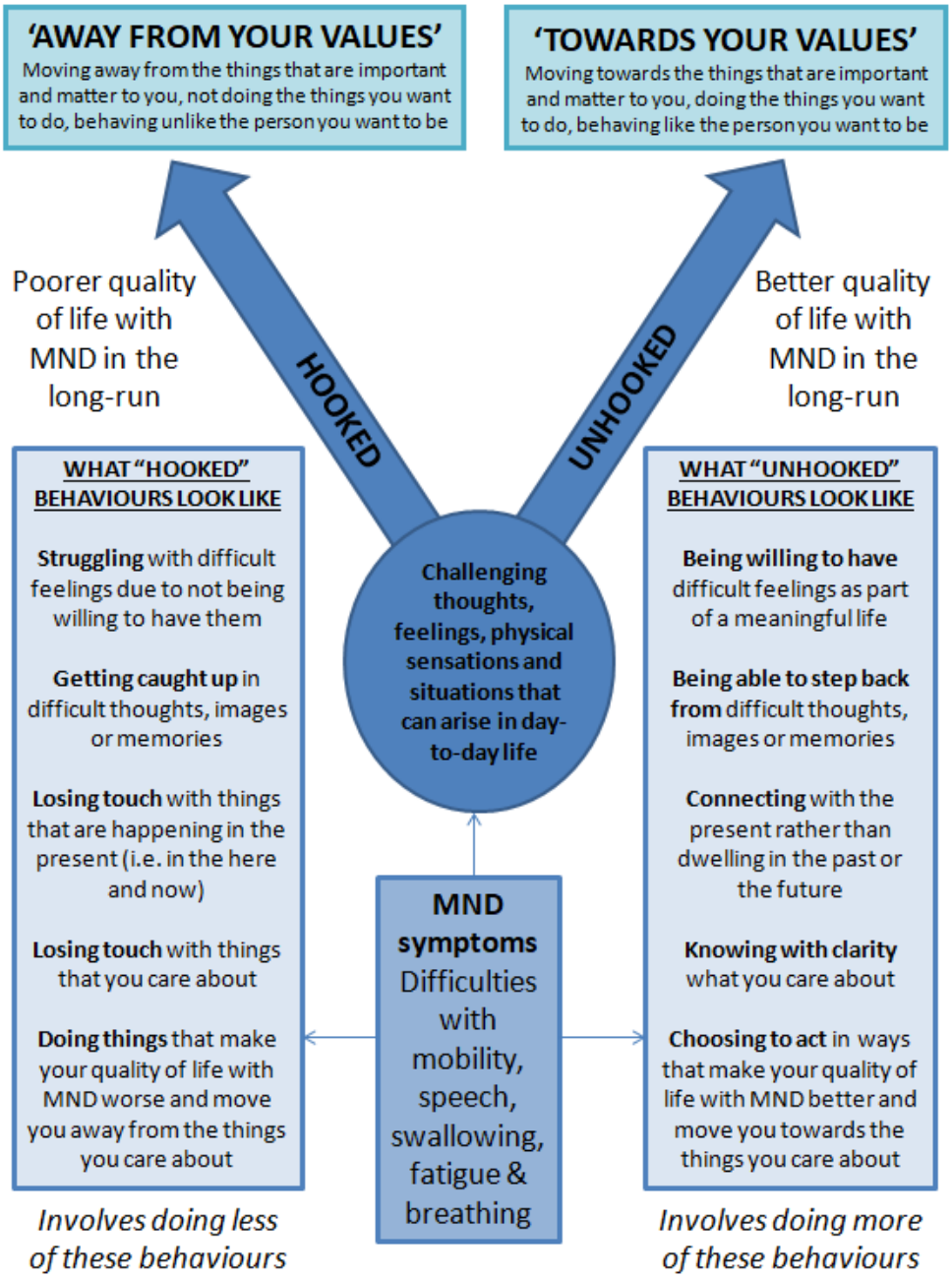
Rationale for Acceptance and Commitment Therapy to be read before completing the CEQ

The aims of Acceptance and Commitment Therapy (ACT, pronounced as the word "act") are to help you to:

1) Identify the things that are important and that matter to you, and the type of person you want to be with MND (i.e. your values), as well as how you are currently living in line with these values;

2) Become more aware of thoughts, feelings, physical sensations and situations that might 'hook you', pull you off track, or pull you away from living your life in line with what is important and matters to you. These might be challenging thoughts, feelings, physical sensations and situations that:
   a. Are getting in the way of you living your life as well as you can with MND now;
   b. Might get in the way of you living your life as well as you can with MND in the future;
   c. Or are holding you back from finding new ways to do what you most want to do or be who you most want to be in your life, alongside MND.

3) Learn new ways of handling these thoughts, feelings, physical sensations and situations in order that you can live your life as well as you can with MND, now and in the future. This will involve learning how to do less of the "hooked" behaviours and more of the "unhooked" behaviours.



COMMEND RCT

Credibility / Expectancy Questionnaire

Baseline

P ☐☐/☐☐☐

We would like you to indicate below how much you believe, *right now*, that the therapy you are receiving will help to improve your quality of life. Belief usually has two aspects to it: (1) what one *thinks* will happen and (2) what one *feels* will happen. Sometimes these are similar; sometimes they are different.

Please answer the questions below. In the first set, answer in terms of what you *think*. In the second set answer in terms of what you really and truly *feel*.

We do not want your therapist to ever see these ratings, so please keep the sheet covered when you are done.

Set I

1. At this point, how logical does the therapy offered to you seem?

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐

not at all logical — somewhat logical — very logical

2. At this point, how successful do you think this treatment will be in improving your quality of life?

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐

not at all useful — somewhat useful — very useful

3. How confident would you be in recommending this treatment to a friend who experiences similar problems?

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐

not at all confident — somewhat confident — very confident

4. By the end of the therapy period, how much improvement in your quality of life do you think will occur?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Devilly, G. J. and T. D. Borkovec (2000). "Psychometric properties of the credibility/expectancy questionnaire." J Behav Ther Exp Psychiatry 31(2): 73-86.

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COMMEND RCT

Credibility / Expectancy Questionnaire

Baseline

P ☐☐/☐☐☐

Set II

For this set, close your eyes for a few moments, and then try to identify what you really *feel* about the therapy and its likely success. Then answer the following questions.

1. At this point, how much do you really *feel* that the therapy will help you improve your quality of life?

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐

not at all — somewhat — very much

2. By the end of the therapy period, how much improvement in your quality of life do you really *feel* will occur?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Devilly, G. J. and T. D. Borkovec (2000). "Psychometric properties of the credibility/expectancy questionnaire." J Behav Ther Exp Psychiatry 31(2): 73-86.

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Treatment preference

Baseline

P ☐☐/☐☐☐

Although you will be chosen at random to have either Acceptance and Commitment Therapy or usual multidisciplinary care alone, if you could choose what treatment you received, how much would you hope to receive Acceptance and Commitment Therapy plus usual multidisciplinary care?

☐ 0 (not at all) ☐ 1 ☐ 2 ☐ 3 (completely)

How much would you hope to receive usual multidisciplinary care alone (i.e. without Acceptance and Commitment Therapy)?

☐ 0 (not at all) ☐ 1 ☐ 2 ☐ 3 (completely)

COMMEND RCT

Randomisation

Baseline

P ☐☐/☐☐☐

Was the participant randomised? ☐ Yes ☐ No

Date ☐☐ ☐☐ ☐☐☐☐
d d m m y y y y

Arm ☐ Intervention ☐ Control

SCRAM Number R ☐☐/☐☐

Participant informed of allocation? ☐ Yes ☐ No

reason

Participant's GP / MND care team informed of allocation? ☐ Yes ☐ No

reason

Reason