A questionnaire about Graded Exercise Therapy guided SElf-help Treatment (GETSET) for patients with chronic fatigue syndrome/myalgic encephalomyelitis.
This questionnaire is about your current health and wellbeing following the diagnosis of chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME).

Please look at the instructions at the beginning of each question; most of the answers just require you to tick a box. Usually you will be asked to choose only one option, and there are no right or wrong answers, so choose the one that best describes you.

All your answers will be kept confidential and will only be seen by members of the research team.

If you have any concerns or queries at any stage of filling out the questionnaire, please ring the GETSET study team on 020 3465 5698 or email: getset@qmul.ac.uk

Thank you for taking the time to complete this questionnaire.

Your time and effort are much appreciated.

GETSET baseline questionnaire version 1
dated 15.01.2012
Section 1
Information about you

Question 1
When did the first symptoms of your current CFS/ME illness start?

Question 2
Have you received any of the treatments listed below from a therapist for your CFS/ME?
Tick as many as appropriate.

A  Pacing therapy or advice on pacing or lifestyle self management  Yes [ ] No [ ]

B  Cognitive Behaviour Therapy (CBT)  Yes [ ] No [ ]

C  Graded Exercise Therapy (GET)  Yes [ ] No [ ]

Question 3
Have you used any of the following resources for your CFS/ME?
Tick as many as appropriate.

Coping with Chronic Fatigue

OVERCOMING CHRONIC FATIGUE

Chronic Fatigue Syndrome (CFE)

Graded Exercise Therapy (GET)

PIN 1
Question 4
Are you currently a member of a local self-help group for CFS/ME? Yes ☐ No ☐

Question 5
Are you currently a member of a national CFS/ME patient organisation? Yes ☐ No ☐

Question 6
Please give details of your ethnicity by ticking one box.

White:
British ☐
Irish ☐
Other ☐

Black or Black British:
Caribbean ☐
African ☐
Other ☐

Asian or Asian British:
Indian ☐
Bangladeshi ☐
Pakistani ☐
Other ☐

Chinese or other ethnic group:
Chinese ☐
Any other ethnic group ☐

Question 7
What is the highest education level you have successfully completed?

None ☐
GCSE/O-level or equivalent ☐
A-level or equivalent ☐
Degree ☐
Postgraduate ☐
Other ☐
If other, please describe ☐
Question 8

A

What is your CURRENT employment status?
Please tick one box only.

Employed or self-employed, full-time and working ............
Employed or self-employed, part-time and working ............
Employed or self-employed, full-time but ‘off-sick’ ..........
Employed or self-employed, part-time but ‘off-sick’ .........
Unemployed .................................................................
Retired (because of age) .............................................
Retired (because of ill health) ....................................
Student ........................................................................
Student but studies interrupted due to illness ..........
Housewife/husband .................................................
Other ...........................................................................
If other, please describe ...........................................

B

Have you had to stop or reduce your work/study in the last 12 weeks
due to your state of ill health? ........................................ Yes □ No □

If yes, please answer EITHER question C or D.

C

How many days in the last 12 weeks have you taken off work/study
because of your CFS/ME? ............................................. days
(There are 60 working days in 12 weeks)

D

How many fewer hours per week have you worked
in the last 12 weeks because of your CFS/ME? ............... hours
Section 2
Your general health

Question 9

By ticking in one box in each group below, please indicate which statements best describe your own health TODAY.

A Mobility
I have no problems in walking about .................................................................
I have some problems in walking about .........................................................
I am confined to bed ........................................................................................

B Self-care
I have no problems with self-care .................................................................
I have some problems washing or dressing myself .......................................
I am unable to wash or dress myself .............................................................

C 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 ..................................................

D Pain/discomfort
I have no pain or discomfort ........................................................................
I have moderate pain or discomfort ..............................................................
I have extreme pain or discomfort .................................................................

E Anxiety/depression
I am not anxious or depressed ....................................................................
I am moderately anxious or depressed ........................................................
I am extremely anxious or depressed ..........................................................
**Question 10**

We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the **PAST MONTH**. Please answer all the questions by ticking the single answer which applies to you most closely. If you have been feeling tired for a long while compare yourself to how you felt when you were last well.

<table>
<thead>
<tr>
<th></th>
<th>Less than usual</th>
<th>No more than usual</th>
<th>More than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have problems with tiredness?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you need to rest more?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel sleepy or drowsy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have problems starting things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you lacking in energy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have less strength in your muscles?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel weak?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty concentrating?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you make slips of the tongue when speaking?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you find it more difficult to find the correct word?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Better than usual</th>
<th>No worse than usual</th>
<th>Worse than usual</th>
<th>Much worse than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is your memory?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Question 11

The following questions are about activities you might do during a TYPICAL DAY.

Please tick one box on each line.

<table>
<thead>
<tr>
<th>Does your health limit you in the following activities?</th>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifting or carrying groceries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing several flights of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing one flight of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bending, kneeling or stooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking more than a mile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking several blocks (several hundred yards)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking one block (one hundred yards)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing or dressing yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. Please think about the activities you do at work, as part of your house and garden work, to get from place to place, and in your spare time for recreation, exercise or sport.

The questions will ask you about the time you spent being physically active in the LAST SEVEN DAYS.

**Question 12**

Think about all the **vigorous** activities that you did in the last seven days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Examples are heavy lifting, digging, aerobics and fast bicycling. Think only about those physical activities that you did for **at least 10 minutes** at a time.

**During the LAST SEVEN DAYS, did you do any VIGOROUS physical activities?**

Yes ☐ No ☐

If yes, please answer question 13.
If no, please go to question 14.

**Question 13**

On how many days did you do VIGOROUS physical activities? .................................. days per week

How much time did you spend doing vigorous physical activities ON AVERAGE during those days?

.................. hours .................. minutes

**Question 14**

Think about all the **moderate** activities that you did in the last seven days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Examples are carrying light loads, bicycling at a regular pace, or doubles tennis. Do not include walking for which there is a separate question. Think only about those physical activities that you did for **at least 10 minutes** at a time.

**During the LAST SEVEN DAYS, did you do any MODERATE physical activities?**

Yes ☐ No ☐

If yes, please answer question 15.
If no, please go to question 16.
Question 15

On how many days did you do MODERATE physical activities? ………… days per week

How much time did you spend doing moderate physical activities ON AVERAGE during those days? ………… hours ………… minutes

Question 16

Think about the time you spent walking in the last seven days. This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise or leisure.

During the LAST SEVEN DAYS, did you do any walking? ……………… Yes☐ ………… No☐

If yes, please answer question 17.
If no, please go to question 18.

Question 17

On how many days did you WALK for at least 10 MINUTES at a time? ………… days per week

How much time did you spend walking ON AVERAGE during those days? ………… hours ………… minutes

Question 18

Think about the time you spent sitting on weekdays during the last seven days. Include time spent at work, at home, while studying and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

During the LAST SEVEN DAYS how much time did you spend sitting on an average weekday? ………… hours ………… minutes
Section 4
How CFS/ME has affected you

Question 19

If you are retired, or choose not to have a job for reasons unrelated to CFS/ME, please tick here

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems please read the following statements and circle the number in each line that best indicates your answer.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Slightly</td>
<td>Definitely</td>
<td>Markedly</td>
<td>Very severely</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Because of my CFS/ME, my ability to work is affected
(Circle 8 if you cannot work at all)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
</table>

Because of my CFS/ME, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is affected

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
</table>

Because of my CFS/ME, my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are affected

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
</table>

Because of my CFS/ME, my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are affected

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
</table>

Because of my CFS/ME, my ability to form and maintain close relationships with others, including those I live with, is affected

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
Question 20

Please read each item and tick the box which comes closest to how you have been feeling during the **past week**. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

<table>
<thead>
<tr>
<th>I feel tense or wound up:</th>
<th>I feel as if I am slowed down:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>From time to time, occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I still enjoy the things I used to enjoy:</th>
<th>I get a sort of frightened feeling like butterflies in my stomach:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Only a little</td>
<td>Quite often</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling as if something awful is about to happen:</th>
<th>I have lost interest in my appearance:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>Definitely</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>I don’t take so much care</td>
</tr>
<tr>
<td>A little, but it doesn’t worry me</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things:</th>
<th>I feel restless as if I have to be on the move:</th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind:</th>
<th>I look forward with enjoyment to things:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
<td>As much as I ever did</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>From time to time but not too often</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>
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 programme:
Often ...................................................... □
Sometimes ............................................... □
Not often ................................................ □
Very seldom ............................................. □

### Question 21

Your answers to these questions will help us measure any concerns you have that physical activity and/or exercise will make your CFS/ME symptoms worse.

Please read the following statements and tick the box in each line that most closely relates to your experience.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am afraid that I might make my symptoms worse if I exercise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I were to try to overcome it, my fatigue would increase</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My body is telling me I have something dangerously wrong</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My fatigue would probably be relieved if I were to exercise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People are not taking my medical condition seriously enough</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness has put my body at risk for the rest of my life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue always means I have harmed my body</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PIN 11
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Just because something increases my fatigue, it does not mean it is dangerous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am afraid I might make my symptoms worse accidentally</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my fatigue from worsening</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would not have this much fatigue if there was not something potentially dangerous going on in my body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Although I am fatigued, I would be better off if I were physically active</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue lets me know when to stop exercising so that I do not harm myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is really not safe for a person with a condition like mine to be physically active</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot do all the things normal people do because its too easy for me to get tired</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Even though something makes me fatigued, I do not think it is actually harming me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No one should have to exercise when he/she is fatigued</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 5
Your medical health

We would like to know more about the medical problems that have bothered you during the last month and whether you have any other illnesses which have not yet been mentioned.

Question 22

During the PAST FOUR WEEKS how much have you been bothered by any of the following problems?

Please tick one box on each line.

<table>
<thead>
<tr>
<th></th>
<th>Not bothered at all</th>
<th>Bothered a little</th>
<th>Bothered a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain in your arms, legs, or joints (knees, hips, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Menstrual cramps or other problems with your periods (women only)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fainting spells</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling your heart pound or race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain or problems during sexual intercourse (if appropriate)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation, loose bowels, or diarrhoea</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Question 23

Do you have any current illnesses, symptoms or health problems not yet mentioned? Yes [ ] No [ ]

If yes, please write the details in the table below

<table>
<thead>
<tr>
<th>Health problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Question 24

Have you been taking antidepressant medication for any purpose, including sleep or pain relief, over the LAST 12 WEEKS?

Yes [ ] No [ ] Not sure [ ]

Name of medicine

---
# Section 6

## Your need for help

Your answers to the following questions will give us information about how much your illness has affected you, those looking after you and society in general.

## Question 25

Please let us know what one-to-one consultations you have had with the following health professionals in the LAST 12 WEEKS.

<table>
<thead>
<tr>
<th>Professional</th>
<th>No</th>
<th>Yes</th>
<th>Number of consultations in the last 12 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>A GP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other doctor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other health professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complementary therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please state what specialty, e.g. cardiologist:

Please state what type, e.g. dentist:

Please state what type, e.g. acupuncturist:

Please state what type, e.g. psychologist, physiotherapist, occupational therapist:
Question 26

Have you spent time as a hospital inpatient in the last 12 WEEKS? Yes ☐ No ☐

If yes, please give us the following information.

<table>
<thead>
<tr>
<th>Hospital name and department</th>
<th>Reason for admission</th>
<th>Total length of stay in days</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. Barts Hospital, neurology department</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Question 27

Have you attended A&E in the last 12 WEEKS? Yes ☐ No ☐

If yes, number of times

Question 28

In the last 12 WEEKS have you received help from friends or relatives for any of the following tasks as a consequence of your CFS/ME?

<table>
<thead>
<tr>
<th>Type of help</th>
<th>No</th>
<th>Yes</th>
<th>Average number of hours help per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care, e.g. washing, dressing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help in and around the house, e.g. cooking, cleaning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help outside the home, e.g. shopping, transport</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please describe:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other, please describe: ........................................
Date you completed this questionnaire

Please return it to us in the envelope provided. You do not need to use a stamp.

Thank you for taking the time to complete this questionnaire.
A questionnaire about Graded Exercise Therapy guided SElf-help Treatment (GETSET) for patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).
Follow-up questionnaire about Graded Exercise Therapy guided SElf-help Treatment (GETSET) for patients with chronic fatigue syndrome/ myalgic encephalomyelitis
This questionnaire is about your current health and wellbeing following your participation in the GETSET study.

Please look at the instructions at the beginning of each question; most of the answers just require you to tick a box. Usually you will be asked to choose only one option, and there are no right or wrong answers, so choose the one that best describes you.

All your answers will be kept confidential and will only be seen by members of the research team.

If you have any concerns or queries at any stage of filling out the questionnaire, please ring the GETSET study team on 020 3465 5698 or email: getset@qmul.ac.uk

Thank you for taking the time to complete this questionnaire.

Your time and effort are much appreciated.
Section 1

Your general health

Question 1

By ticking in one box in each group below, please indicate which statements best describe your own health TODAY.

A Mobility
I have no problems in walking about .................................................................
I have some problems in walking about ........................................................
I am confined to bed ........................................................................................

B Self-care
I have no problems with self-care ..............................................................
I have some problems washing or dressing myself .................................
I am unable to wash or dress myself ...........................................................

C 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 ..............................................

D Pain/discomfort
I have no pain or discomfort ...................................................................
I have moderate pain or discomfort ........................................................
I have extreme pain or discomfort ............................................................

E Anxiety/depression
I am not anxious or depressed ............................................................... 
I am moderately anxious or depressed ...................................................
I am extremely anxious or depressed .....................................................
**Question 2**

We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the **PAST MONTH**. Please answer all the questions by ticking the single answer which applies to you most closely.

If you have been feeling tired for a long while compare yourself to how you felt when you were last well.

<table>
<thead>
<tr>
<th>Question</th>
<th>Less than usual</th>
<th>No more than usual</th>
<th>More than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have problems with tiredness?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you need to rest more?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel sleepy or drowsy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have problems starting things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you lacking in energy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have less strength in your muscles?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel weak?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty concentrating?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you make slips of the tongue when speaking?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you find it more difficult to find the correct word?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How is your memory?</td>
<td>Better than usual</td>
<td>No worse than usual</td>
<td>Worse than usual</td>
<td>Much worse than usual</td>
</tr>
</tbody>
</table>

2 PIN
Question 3

A Overall, how much do you feel your health has changed since the start of the study? Please tick the one box below that most closely corresponds to how you feel now.

- Very much better
- Much better
- A little better
- No change
- A little worse
- Much worse
- Very much worse

B Overall, how much do you feel your CFS/ME has changed since the start of the study? Please tick the one box below that most closely corresponds to how you feel now.

- Very much better
- Much better
- A little better
- No change
- A little worse
- Much worse
- Very much worse
# Section 2

## Your physical activities

### Question 4

The following questions are about activities you might do during a TYPICAL DAY.

Please tick one box on each line.

<table>
<thead>
<tr>
<th>Does your health limit you in the following activities?</th>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vigorous activities</strong>, such as running, lifting heavy objects, participating in strenuous sports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Moderate activities</strong> such as moving a table, pushing a vacuum cleaner, bowling or playing golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifting or carrying groceries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing <em>several</em> flights of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing <em>one</em> flight of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bending, kneeling or stooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking <em>more</em> than a mile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking <em>several</em> blocks (<em>several</em> hundred yards)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking <em>one</em> block (<em>one</em> hundred yards)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing or dressing yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. Please think about the activities you do at work, as part of your house and garden work, to get from place to place, and in your spare time for recreation, exercise or sport.

The questions will ask you about the time you spent being physically active in the LAST SEVEN DAYS.

**Question 5**

Think about all the **vigorous** activities that you did in the last seven days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Examples are heavy lifting, digging, aerobics and fast bicycling. Think only about those physical activities that you did for **at least 10 minutes** at a time.

**During the LAST SEVEN DAYS, did you do any VIGOROUS physical activities?** ................................................................. Yes ☐ .......... No ☐

If yes, please answer **question 6**.
If no, please go to **question 7**.

**Question 6**

On how many days did you do VIGOROUS physical activities? .............................. days per week

How much time did you spend doing vigorous physical activities ON AVERAGE during those days? .............................. hours ............ minutes

**Question 7**

Think about all the **moderate** activities that you did in the last seven days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Examples are carrying light loads, bicycling at a regular pace, or doubles tennis. Do not include walking for which there is a separate question. Think only about those physical activities that you did for **at least 10 minutes** at a time.

**During the LAST SEVEN DAYS, did you do any MODERATE physical activities?** ................................................................. Yes ☐ .......... No ☐

If yes, please answer **question 8**.
If no, please go to **question 9**.
Question 8

On how many days did you do MODERATE physical activities? ......................... days per week

How much time did you spend doing moderate physical activities ON AVERAGE during those days? .................. hours ................. minutes

Question 9

Think about the time you spent walking in the last seven days. This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise or leisure.

During the LAST SEVEN DAYS, did you do any walking? ......................... Yes ☐ ............. No ☐

If yes, please answer question 10.
If no, please go to question 11.

Question 10

On how many days did you WALK for at least 10 MINUTES at a time? .................. days per week

How much time did you spend walking ON AVERAGE during those days? .................. hours ................. minutes

Question 11

Think about the time you spent sitting on weekdays during the last seven days. Include time spent at work, at home, while studying and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

During the LAST SEVEN DAYS how much time did you spend sitting on an average weekday? .................. hours ................. minutes
Section 3
How CFS/ME has affected you

Question 12

If you are retired, or choose not to have a job for reasons unrelated to your CFS/ME, please tick here

People’s problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems please read the following statements and circle the number in each line that best indicates your answer.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Slightly</td>
<td>Definitely</td>
<td>Markedly</td>
<td>Very severely</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Because of my CFS/ME, my ability to **work** is affected
(Circle 0 if you cannot work at all)

Because of my CFS/ME, my **home management** (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is affected

Because of my CFS/ME, my **social leisure activities** (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are affected

Because of my CFS/ME, my **private leisure activities** (done alone, such as reading, gardening, collecting, sewing, walking alone) are affected

Because of my CFS/ME, my ability to form and maintain **close relationships** with others, including those I live with, is affected

PIN

7
Question 13

Please read each item and tick the box which comes closest to how you have been feeling during the PAST WEEK. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

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 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 my 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 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 .............................................................................

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

I have lost interest in my appearance:
Definitely ..........................................................................
I don’t take so much care as I should .........................
I may not take quite as much care .............................
I take just as much care as ever ................................

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 programme:
Often .............................................................
Sometimes ......................................................
Not often ..........................................................
Very seldom ......................................................
Section 4
Your medical health

We would like to know more about the medical problems that have bothered you during the last month and whether you have any other illnesses which have not yet been mentioned.

Question 14

During the PAST FOUR WEEKS how much have you been bothered by any of the following problems?

Please tick one box on each line.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not bothered at all</th>
<th>Bothered a little</th>
<th>Bothered a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain in your arms, legs, or joints (knees, hips, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Menstrual cramps or other problems with your periods (women only)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fainting spells</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling your heart pound or race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain or problems during sexual intercourse (if appropriate)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation, loose bowels, or diarrhoea</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Question 15

Since the start of the GETSET study, have you had new health problems? ................................................................. Yes ☐ No ☐

If yes, please write the details in the table below

<table>
<thead>
<tr>
<th>Health problem</th>
<th>Time it lasted in days</th>
<th>Was the problem related to your following the GET guide?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes ☐ No ☐ Maybe ☐ N/A ☐</td>
</tr>
<tr>
<td>Nausea, gas, or indigestion</td>
<td></td>
<td>Yes ☐ No ☐ Maybe ☐ N/A ☐</td>
</tr>
<tr>
<td>Feeling tired or having low energy</td>
<td></td>
<td>Yes ☐ No ☐ Maybe ☐ N/A ☐</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td></td>
<td>Yes ☐ No ☐ Maybe ☐ N/A ☐</td>
</tr>
</tbody>
</table>

Question 16

Have you been taking antidepressant medication for any purpose, including sleep or pain relief, over the LAST 12 WEEKS?

Yes ☐ No ☐ Not sure ☐

Name of medicine .................................................................................................................................

PIN 11
Question 17

Please let us know what one-to-one consultations you have had with the following health professionals in the LAST 12 WEEKS.

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Number of consultations in the last 12 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>A GP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other doctor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please state what specialty, e.g. cardiologist:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other health professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please state what type, e.g. dentist:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complementary therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please state what type, e.g. acupuncturist:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please state what type, e.g. psychologist, physiotherapist, occupational therapist:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Question 18**

Have you spent time as a hospital inpatient in the last 12 WEEKS?  

[ ] Yes  
[ ] No

If yes, please give us the following information.

<table>
<thead>
<tr>
<th>Hospital name and department</th>
<th>Reason for admission</th>
<th>Total length of stay in days</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. Barts Hospital, neurology department</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**Question 19**

Have you attended A&E in the last 12 WEEKS?  

[ ] Yes  
[ ] No

If yes, number of times ........................................

---

**Question 20**

In the last 12 WEEKS have you received help from friends or relatives for any of the following tasks as a consequence of your CFS/ME?

<table>
<thead>
<tr>
<th>Type of help</th>
<th>No</th>
<th>Yes</th>
<th>Average number of hours help per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care, e.g. washing, dressing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help in and around the house, e.g. cooking, cleaning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help outside the home, e.g. shopping, transport</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please describe:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[ ] PIN

13
Question 21

How satisfied were you with the help you received from this clinic for your CFS/ME during this research study?

Please tick one box only.

Very satisfied .......................................................... □
Moderately satisfied .............................................. □
Slightly satisfied ..................................................... □
Neither ................................................................. □
Slightly dissatisfied ............................................... □
Moderately dissatisfied .......................................... □
Very dissatisfied ..................................................... □
I did not receive help ............................................ □
Section 6
Information about you

Question 22

Since the start of the GETSET study, have you used any of the following resources for your CFS/ME?
Tick as many as appropriate.

[Images of different books]

Question 23

If you received the GET guide, how well did you follow the advice given – did you actually manage to do what had been suggested in the guided support sessions?

Please tick one box only.

Completely .................................................. [ ]
Very well ...................................................... [ ]
Moderately well ........................................... [ ]
Slightly ....................................................... [ ]
Not at all ..................................................... [ ]
I did not receive the guide ............................ [ ]
Question 24

A. What is your CURRENT employment status?
   Please tick one box only.

   Employed or self-employed, full-time and working .......... ☐
   Employed or self-employed, part-time and working .......... ☐
   Employed or self-employed, full-time but ‘off-sick’ .......... ☐
   Employed or self-employed, part-time but ‘off-sick’ .......... ☐
   Unemployed ............................................................................ ☐
   Retired (because of age) .......................................................... ☐
   Retired (because of ill health) .................................................. ☐
   Student .................................................................................. ☐
   Student but studies interrupted due to illness ...................... ☐
   Housewife/husband ............................................................... ☐
   Other .................................................................................... ☐
   If other, please describe ____________________________________

B. Have you had to stop or reduce your work/study in the last 12 weeks
due to your state of ill health? .................................................. Yes ☐ No ☐

   If yes, please answer EITHER question C or D.

C. How many days in the last 12 weeks have you taken off work/study
because of your CFS/ME? ......................................................... days

   (There are 60 working days in 12 weeks)

D. How many fewer hours per week have you worked
because of your CFS/ME in the last 12 weeks?

   ........................................ hours
Please write here any comments you would like to make.

Date you completed this questionnaire

Please return it to us in the envelope provided. You do not need to use a stamp.

Thank you for taking the time to complete this questionnaire.
Follow-up questionnaire about Graded Exercise Therapy guided SElf-help Treatment (GETSET) for patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).