## Leger ME ME/CFS grading based in the Finley and NICE systems

<u>Grade</u>	<u>Description</u>	Ability of Patient	<u>%</u>	<u>DLA</u>	<u>Daily</u> Personal <u>Minimal</u> <u>Care</u>	Home Life	Quality Leisure Time	Work Ability
0	Normal	Lives a 'normal' life.		None	Normal	Normal	Normal	Full time
1	Mild	Mobile and self caring and able to manage light domestic and work tasks, with difficulty	25- 33%	Low Rate Mobility	Can cope with Personal care, but rationed.	Trade off against work.	May be severely rationed	Part time
2	Moderate	Reduced mobility and restricted in all activities of daily living, often having peaks and troughs of ability, dependent on degree of symptoms.  Usually stopped work or limited capacity, requiring many rest periods.	50– 60%	High Rate Mobility Low Rate Care	Rationed personal Care	Rationed	Often Minimal	Some possible in protected environment or maybe from home in certain circumstances
3	Severe	Will be able to carry out minimal daily tasks, i.e. face -washing, cleaning teeth, has severe cognitive difficulties and is wheelchair -dependent for mobility. Frequently often unable to leave the house.	25%	High Mobility Middle Rate Care	Many need intervention from others. Personal Care and meals	Minimal	Some but severely restricted	Occasional voluntary when and if able with support and protected environment.
4	Very Severe	Unable to mobilize or carry out any daily task for themselves. Bedridden the majority of the time.	1-2%	High Mobility High Rate Care	Needs intervention from others 24/7	Zero	Zero	None

The chances of recovery based on Leger ME Experience

<u>History</u>	Most Common Outcome
Child or Young adult acute onset	Expect Peak at around 18 months, full recovery possible in 3-5 years, but may not be complete.
Middle age Adult, acute onset	Expect peak at 2 years, and slow, partial or incomplete recovery.
Older acute onset	Expect peak at 2 years, with incomplete recovery influenced by age.
Insidious Onset	Expect the condition will become chronic with poor chance of full recovery.
Long established ME/CFS or duration > 4 years	Chronic, lifelong, may be periods of remission or relapse
Pre-existing Atopic disease history e.g. multiple allergies, asthma, psoriasis eczema	Expect partial recovery after 2 years, with the condition becoming chronic, and following the peaks and troughs of the atopic disease.
Later life or age related conditions cardiovascular, arthritis, diabetes.	Expect partial recovery, and chronic common shared symptoms more severe than would be expected for their age related condition.

# Part 1 – Physical functions

## 1. Moving around and using steps

By moving we mean including the use of aids such as a manual wheelchair, crutches or a walking stick, if you usually use one, but without the help of another person.

Please tick this box if you can		✓	Now go to question 2.	Clear this box for this section to count			
move around and use steps without difficulty.			The laws says that the following	g points tariff applies:			
Can you move at least 50 metres (about 54 yards)	No		1) Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid can reasonably be used.				
before you need to stop?	Yes			more than 50 metres on level ground without			
To give you an idea about distances: A double-decker bus is about 11 metres long.	It varies		stopping in order to avoid significant discomfort or exhaustion; or (ii) repeatedly mobilise 50 metres within a reasonable time scale because of significant discomfort or exhaustion. 15 (b) Cannot mount or descend two steps unaided by another person even with the support of a handrail. 9 (c) Cannot either: (i) mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or (ii) repeatedly mobilise 100 metres within a reasonable time scale because of significant discomfort or exhaustion.9 (d) Cannot either: (i) mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or (ii) repeatedly mobilise 200 metres within a reasonable time scale because of significant discomfort or exhaustion. 6 (e) None of the above apply. 0				
Can you move at least 200 metres (about 220 yards)	No						
before you need to stop?	Yes						
To give you an idea about distances: A double-decker bus is about 11 metres long.	It varies						

Use this space to tell us how far you can move and why you might have to stop. For example tiredness or discomfort. If it varies, tell us how. Tell us if you usually use a walking stick, crutches, a wheelchair or anything else to help you, and tell us how it affects the way you move around.

#### Going up or down two steps

Can you go up or down two steps without help from another person, if there is a rail to hold on to?

No

Yes

Now go to question 2.

lt

varies

Use this space to tell us more about using steps. If it varies, tell us how.

ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
Moving around & using steps	Pain, dizziness tremor, muscle weakness rebound, cognitive, confusion.	<200 meters (6)	<50 meters (15) <100 meters (9)	<50 meters (15) No Steps (15)

#### 2. Standing and sitting

Clear this box for this section to count Please tick this box if you can stand Now go to question 3. and sit without difficulty. The laws says that the following points tariff applies: 2. Standing and sitting. Can you move from one seat to No another right next to it without (a) Cannot move between one seated position and another seated position help from someone else? Yes located next to one another without receiving physical assistance from another person. 15 It (b) Cannot, for the majority of the time, remain at a work station, either: varies (i) standing unassisted by another person (even if free to move around); or (ii) sitting (even in an adjustable chair) for more than 30 minutes, Can you stay in one place, No before needing to move away in order to avoid significant discomfort or exhaustion. 9 either standing or sitting, for (c) Cannot, for the majority of the time, remain at a work station, either: (i) at least an hour without help Yes standing unassisted by another person (even if free to move from another person? around); or (ii) sitting (even in an adjustable chair) for more than an hour It This does not mean standing varies before needing to move away in order to avoid significant completely still. It includes discomfort or exhaustion. 6 being able to change position. (d) None of the above apply 0

Use this space to tell us more about standing and sitting and why this might be difficult for you. Tell us how long you can sit for and how long you can stand for. Tell us what might make it difficult for you, such as pain, discomfort or tiredness. If it varies, tell us how.

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
2	Standing and sitting.	Pain, dizziness stiffness discomfort. muscular weakness	Cannot sit for most of the time (6)	Sit <30 minutes (9)	Sit or stand < 10 minutes(15) Can't rise or move

### 3. Reaching

Clear this box for this section to count Please tick this box if you can reach up Now go to question 4. with your arms without difficulty. The laws says that the following points tariff applies: Can you lift at least one of No your arms high enough to put 3. Reaching. something in the top pocket Yes of a coat or jacket while you (a) Cannot raise either arm as if to put something in the top lt are wearing it? pocket of a coat or jacket. 15 varies (b) Cannot raise either arm to top of head as if to put on a Can you lift one of your No (c) Cannot raise either arm above head height as if to reach for something. 6 arms above your head (d) None of the above apply. 0 to reach for something? Yes varies

Use this space to tell us more. Tell us why you might not be able to reach up, and whether it affects both arms. If it varies, tell us how.

### 4. Picking up and moving things

Please tick this box if you can pick things up and move them without difficulty.

Now go to question 5.

Clear this box for this section to count

#### Picking up things using your upper body and either arm

Can you pick up and move a half-litre (one pint) carton full of liquid?

No

Yes

It varies

The laws says that the following points tariff applies:

Can you pick up and move

No

4. Picking up and moving or transferring by the use of the upper body and arms.

a litre (two pint) carton full of liquid?

Yes

(a) Cannot pick up and move a 0.5 litre carton full of liquid. 15 (b) Cannot pick up and move a one litre carton full of liquid. 9 (c) Cannot transfer a light but bulky object such as an empty

Ιt varies cardboard box. 6 (d) None of the above apply. 0

Can you pick up and move a large, light object like an

empty cardboard box?

No

Yes

It varies

Use this space to tell us more about picking things up and moving them. Tell us why you might not be able to pick things up. If it varies, tell us how.

	ESA 50/2	ME/CFS issues	<u>Grade 2</u>	Grade 3	Grade 4
4)	Picking up and moving things.	Clumsiness, manual dexterity, weakness tremor, fasciculation, myoclonus	Light bulky object (6)	Litre liquid(9)	Pint liquid (15)

## 5. Manual Dexterity (Using your hands)

Please tick this box if you can use your hands without any difficulty.

Now go to question 6.

Clear this box for this section to count

Can you use either hand to do things like:

Some of them

It varies

The laws says that the following points tariff applies:

5. Manual dexterity.

press a button, such as a telephone keypad turn the pages of a book pick up a £1 coin use a pen or pencil use a computer keyboard

or computer mouse?

None of them (a) Cannot either: (i) press a button, such as a telephone keypad;

or (ii) turn the pages of a book with either hand. 15 (b) Cannot pick up a £1 coin or equivalent with either hand. 15

(c) Cannot use a pen or pencil to make a meaningful mark. 9

(d) Cannot use a suitable keyboard or mouse. 9

(e) None of the above apply. 0

Use this space to tell us more. Tell us which of these things you have problems with and why. If it varies, tell us how.

**ESA 50/2** ME/CFS issues Clumsiness, manual dexterity, Manual dexterity. weakness tremor, fasciculation, myoclonus

Grade 2 Grade 3

Grade 4 Meaningful mark(9) Buttonton, coin or book

(15)

#### 6. Communicating with people

This section looks at how you communicate using speech, writing and typing.

No

Yes

varies

lt

Please tick this box if you can communicate with other people without any difficulty.

Can you communicate with someone you don't know by speaking, writing, typing or any other means without the help of another person? ✓ No

Now go to question 7.

Clear this box for this section to count

The laws says that the following points tariff applies:

- 6. Making self understood through speaking, writing, typing, or other means normally used, unaided by another person.
- (a) Cannot convey a simple message, such as the presence of a hazard. 15
- (b) Has significant difficulty conveying a simple message to strangers. 15
- (c) Has some difficulty conveying a simple message to strangers.
- (d) None of the above apply. 0

Use this space to tell us more about how you communicate and why you might not be able to communicate with other people. For example, difficulties with speech, writing or typing. If it varies, tell us how.

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
5)	Communicating with people	Pausing mid sentence, forgetting or can't find right word. talk out of context		Stranger some difficulty (6)	Strangers significant difficulty (15) Can't convey simple messages(15)

### 7. Other people communicating with you

This section looks at how you understand other people by hearing and reading.

Nο

Yes

It

Please tick this box if you can understand other people without any difficulty.

Can you understand other people – by hearing, lip reading, reading or using a hearing aid without the help of another person?

Now go to question 8.

Clear this box for this section to count

varies

Use this space to tell us more. Tell us if you can hear, lip read, read or understand people in another way, or why you might not be able to. Tell us about any aids you use, such as a hearing aid. If it varies, tell us how.

The laws says that the following points tariff applies:

- 7. Understanding communication by both verbal means (such as hearing or lip reading) and nonverbal means (such as reading 16 point print) using any aid it is reasonable to expect them to use, unaided by another person.
- (a) Cannot understand a simple message due to sensory impairment, such as the location of a fire escape. 15
- (b) Has significant difficulty understanding a simple message from a stranger due to sensory impairment. 15
- (c) Has some difficulty understanding a simple message from a stranger due to sensory impairment. 6
- (d) None of the above apply. 0

ESA 50/2

ME/CFS issues

Grade 2

Grade 3

Grade 4

Other people commutating with you

Hyperacusis, competing noise, concentration

Has difficulty in understanding simple message from stranger (6)

Can't understand or has difficulty understanding simple message (15)

6)

#### 8. Getting around safely

This section looks at visual problems. If you normally use glasses or contact lenses, a guide dog or any other aid, tell us how you manage when you are using them. Please also tell us how you see in daylight or bright electric light.

Please tick this box if you can Now go to question 9. get around safely on your own. Clear this box for this section to count Can you see to cross the road No on your own? Yes It varies Can you get around a place No that you haven't been to before without help? Yes Ιt varies

The laws says that the following points tariff applies:

- 8. Navigation and maintaining safety, using a guide dog or other aid if normally used.
- (a) Unable to navigate around familiar surroundings, without being accompanied by another person, due to sensory impairment. 15 (b) Cannot safely complete a potentially hazardous task such as crossing the road, without being accompanied by another person, due to sensory impairment. 15 (c) Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment. 9

(d) None of the above apply. 0

Use this space to tell us more about any problems with your eyesight and how they stop you finding your way around safely.

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
8)	Getting around safely	Photophobia, eye fatigue quickly, loose ability to focus, glasses don't help		Can't Navigate unfamiliar places (9)	Can't get around with help from another person (15)

## 9. Controlling your bowels and bladder and using a collecting device

Please tick this box if you can control your bowels and bladderwithout any difficulty.

Do you have to wash or change your clothes because of difficulty controlling your bladder, bowels or collecting

Weekly

Monthly

Less often

device? A collecting device is also known as a stoma.

Use this space to tell us more about controlling your bowels and bladder and managing your collecting device.

Tell us how often you might need to change your clothes or wash because of soiling, wetting or leakages.

The laws says that the following points tariff applies:

9. Absence or loss of control leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bed-wetting) despite the presence of any aids or adaptations normally used.

Clear this box for this section to count

- (a) At least once a month experiences: (i) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or (ii) substantial leakage of the contents of a collecting device sufficient to require cleaning and a change in clothing. 15
- (b) At risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change in clothing, if not able to reach a toilet quickly. 6
- (c) None of the above apply. 0

Now go to question 10.

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
9)	Continence	Leaking, wearing pads	Caught short 1x monthly (6)	Caught short 1x monthly (6) Caught short 1x weekly (15)	Caught short 1x weekly (15) No control(15)

Clear this box for

#### 10. Staying conscious when awake

Please tick this box if you do not have any problems staying conscious while awake.

While you are awake, how often do you have fits or blackouts?

Monthly This includes epileptic fits and

absences, and diabetic hypos. Less than monthly

Weekly

Use this space to tell us more.

Now go to question 11 in Part 2

The laws says that the following points tariff applies:

10. Consciousness during waking moments.

(a) At least once a week, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration, 15

(b) At least once a month, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration. 6

(c) None of the above apply. 0.

ESA 50/2	ME/CFS issues	Grade 2	Grade 3	<u>Grade 4</u>
Staying conscious while awake	Drowsy in a morning. sleep during day.	1 weekly (15) 1 month (6)	1 weekly (15) 1 month (6)	1 weekly (15)

### Part 2 – Mental, cognitive and intellectual functions

By mental, cognitive and intellectual functions we mean things like mental illness, learning difficulties and the effects of head injuries.

#### 11. Learning how to do tasks

Please tick this box if you can learn to do everyday tasks without difficulty.

Can you learn how to do a simple task such as setting an

alarm clock? Yes

> It varies

Can you learn how to do a more complicated task such as using a washing machine? No

No

Yes

varies

Now go to question 12.

Clear this box for this section to count

The laws says that the following points tariff applies:

11. Learning tasks.

(a) Cannot learn how to complete a simple task, such as setting an alarm clock. 15

(b) Cannot learn anything beyond a simple task, such as setting an alarm clock. 9

(c) Cannot learn anything beyond a moderately complex task, such as the steps involved in operating a washing machine to clean clothes. 6

(d) None of the above apply. 0

Use this space to tell us about any difficulties you have learning to do tasks, and why you find it difficult.

ESA 50/2 ME/CFS issues Grade 2 **Grade 3** Grade 4 Can operate washing Cant set alarm clock Attentions span limited Learning how to do machine (6) Confusion, (15)tasks

10)

11)

without awareness, aphasia

Cant learn to et alarm clock(15)

### 12. Awareness of hazard or danger

Please tick this box if you can keep yourself safe when doing everyday tasks such as cooking.

Do you need supervision (someone to stay with you) to keep yourself safe?

Usually

**Sometimes** 

It varies

Use this space to tell us how you cope with danger. Please give us examples of problems you have with doing things safely.

Now go to question 13.

Clear this box for this section to count

ESA 50/2	<u>ME/CFS issues</u>	<u>Grade 2</u>	<u>Grade 3</u>	<u>Grade 4</u>	
Awareness of	Concentration span limited.	Needs supervision	Needs supervision daily	Needs supervision	
hazard or danger.	Inna appropriate Automaton action	occasionally(6)	(9)	majority of time(10)	

The laws says that the following points tariff applies:

- 12. Awareness of everyday hazards (such as boiling water or sharp objects).
- (a) Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or(ii) damage to property or possessions such that they require supervision for the majority of the time to maintain safety. 15
- (b) Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or (ii) damage to property or possessions such that they frequently require supervision to maintain safety. 9
- (c) Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or (ii) damage to property or possessions such that they occasionally require supervision to maintain safety.6
- (d) None of the above apply. 0

12)

#### 13. Initiating actions

This section is about whether you can manage to start and complete daily routines and tasks like getting up, washing and dressing, cooking a meal or going shopping.

Please tick this box if you manage to do daily tasks without difficulty.

Can you manage to plan, start and finish daily tasks? Never

**Sometimes** 

It varies

tasks. May avoid activities. EMS, and later fatigue kicks in

Use this space to tell us what difficulties you have doing your daily routines. For example, remembering to do things, planning and organising how to do them, and concentrating to finish them. Tell us what might make it difficult for you and how often you need other people to help you.

Now go to question 14.

Clear this box for this section to count

The laws says that the following points tariff applies:

- 13. Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks).
- (a) Cannot, due to impaired mental function, reliably initiate or complete at least 2 sequential personal actions. 15
- (b) Cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions for the majority of the time. 9
- (c) Frequently cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions. 6
- (d) None of the above apply. 0

#### ESA 50/2 ME/CFS issues Grade 2 Grade 3 Grade 4 Sleep morning or during day Cant do 2 Cant do 2 sequential Short terms memory. sequential Cant do 2 seguential Initiating action Fatigue limits ability to complete some of time(9) frequently (6) actions(15)

## 14. Coping with change

Please tick this box if you can cope with change to your daily routine.

Can you cope with small No changes to your routine if you know about them before they happen?

For example, things like having a lt varies

Can you cope with small changes to your routine if they are unexpected?

This means things like appointments being cancelled,

or your bus or train not running

✓ Now go to question 15.

Clear this box for this section to count

The laws says that the following points tariff applies:

- 14. Coping with change.
- (a) Cannot cope with any change to the extent that day to day life cannot be managed. 15
- (b) Cannot cope with minor planned change (such as a prearranged change to the routine time scheduled for a lunch break), to the extent that overall day to day life is made significantly more difficult. 9
- (c) Cannot cope with minor unplanned change (such as the timing of an appointment on the day it is due to occur), to the extent that overall, day to day life is made significantly more difficult. 6 (d) None of the above apply. 0

Use this space to tell us more about how you cope with change. Explain your problems, and give examples if you can.

varies

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
14)	Coping with change.	Early Morning Stiffness. Not easy to learn new behaviours disruptions	Can't cope minor planned changes (6)	Can't cope minor changes if planned (9)	expected changes (15)

## 15. Going out

Please tick this box if you can go out 

Now go to question 16.

Clear this box for this section to count

on your own. The laws says that the following points tariff applies: Can you leave home and No go out to places you 15. Getting about. Yes know if someone goes with you? 15 (a) Cannot get to any specified place with which It the claimant is familiar. 15 varies (b) Is unable to get to a specified place with which the claimant is familiar, without being accompanied by another person. 9 Can you leave home on Usually (c) Is unable to get to a specified place with which the your own and go to claimant is unfamiliar without being accompanied by places you don't know? another person. 6 Not very often (d) None of the above apply. It varies

Use this space to tell us why you cannot always get to places

. Tell us whether you need someone to go with you.

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
15)	Going out	Anxiety, dizziness, fatigue if driven		Cannot get to a familiar place without supervision (6)	Cannot get to specified without accompaniment (9) Cannot get to familiar place(15)

## 16. Coping with social situations

By *social situations* we mean things like meeting new people and going to meetings or appointments.

Please tick this box if you can o social situations.	ope with 🗸	Now go to question 17.	Clear this box for this section to count	
Can you meet with people you know without feeling too anxious or scared?	No Yes	The laws says that the following points tariff applies:  16. Coping with social engagement due to cognitive impairment or mental disorder.  (a) Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the individual. 15  (b) Engagement in social contact with someone unfamiliar to the claimant is always precluded due to difficulty relating to others or significant distress experienced by the individual. 9  (c) Engagement in social contact with someone unfamiliar to the claimant is not possible for the majority of the time due to difficulty relating to others or significant distress experienced by the individual. 6  (d) None of the above apply. 0		
	It varies			
Can you meet with people you don't know without feeling too	No Yes			
anxious or scared?	It varies			

Use this space to tell us why you find it distressing to meet other people and what makes it difficult. Tell us how often you feel like this

	ESA 50/2	ME/CFS issues	Grade 2	Grade 3	Grade 4
16)	Coping with social situations.	Fatigue, pacing strategies don't dress, Anxiety, phobia. concentration	Social engagement sometimes not possible with strangers (6)	Social engagement preclude /distressing (9)	Precluded (15)

### 17. Behaving appropriately with other people

This section looks at whether your behaviour upsets other people.

Clear this box for this section to count

Please tick this box if your behaviour does not upset other people.

How often do you behave in a way which upsets other people?

For example, this might be because you are aggressive or act in an unusual way.

Every day

Often

Occasionally

Please go the **Other Information** section.

The laws says that the following points tariff applies:

- 17. Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder.
- (a) Has, on a daily basis, uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 15
- (b) Frequently has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 15
- (c) Occasionally has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 9 (d) None of the above apply. 0.

(15)

behaviour 7/7 (15)

Use this space to tell us why your behaviour upsets other people and how often this happens.

ESA 50/2 **ME/CFS** issues Grade 2 **Grade 3** Grade 4 Occasional Uncontrolled **Behaviour** Uncontrolled Usually depressive, and phobia. disinhibited unreasonable behaviour unreasonable appropriately with tend to be irritated. Sleep workplace

behaviour (9)

other people.