

## Part 1. Physical ability scale

<b>The HFME 3 Part M.E. ability &amp; severity scale: PART 1 - PHYSICAL ABILITY SCALE</b>	
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<b>FULLY RECOVERED</b>	
100%	A pre-illness level of physical activity is possible.
<b>VIRTUALLY RECOVERED</b>	
90%	A high level of physical capabilities (around 90%): full-time study or work without difficulty is achievable in addition to a full and active social life.
<b>MILDLY AFFECTED</b>	
80%	A high level of physical activity is possible (around 80%) with minimal restrictions involving exertion. Patient is capable of working full time in jobs not requiring exertion.
70%	Physical activity is at/or around 70%. A daily activity limit is clearly noted. Incapable of full-time work in jobs requiring physical exertion, but able to work full-time in lighter activities if hours are flexible. Social life is restricted to non-exertive activities.
<b>MODERATELY AFFECTED</b>	
60%	Physical activity is at/or around 60%: strenuous activities are difficult, but light activities and desk work are achievable as long as the total time worked is 5 – 7 hours a day and regular rest periods are taken. Physical abilities degenerate significantly with sustained exertion.
50%	Physical activity is at/or around 50%: part-time work, light activities or desk work are acceptable for up to 4 - 5 hours a day as long as requirements for quiet and rest are met. Physically undemanding social activities are possible. Physical abilities degenerate significantly with sustained exertion. Unable to perform strenuous tasks.
<b>MODERATELY TO SEVERELY AFFECTED</b>	
30%	Overall activity level reduced to at/or around 30 - 40%. May be unable to walk without support much beyond 100/200 metres; a walking stick or wheelchair may be used to travel longer distances. Several hours of desk work may be possible each day if requirements for quiet and resting are met. Physically undemanding social activities are possible.
20%	Overall physical activity level reduced to around 20%. Not confined to the house but may be unable to walk without support much beyond 50/100 metres; a wheelchair may be used to travel longer distances. Requires 3 or 4 regular rest periods during the day; only one 'large' activity possible per day usually requiring a day or more of rest. (A large activity is individual; it could be cleaning cupboards or having visitors; it is any activity that the patient finds difficult and so no longer considers 'usual'.)
<b>SEVERELY AFFECTED</b>	
10%	Overall physical activity level reduced to around 10%. Confined to the house but may occasionally (and with a significant recovery period) be able to take a short wheelchair ride or walk, or be taken to see a doctor. Most of the day needs to be spent resting except for a period of several hours interspersed throughout the day when small tasks may be completed (or one larger one). Activity is mostly restricted to managing the tasks of daily living where some assistance is needed and modification of tasks may be required.
5%	Overall physical activity level reduced to around 5%. Usually confined to the house but may very occasionally (with a recovery period of a week or more) be able to take a short wheelchair ride or walk, or be taken to see a doctor. Bed-bound or couch-bound for 21+ hours a day. Activity is restricted almost exclusively to managing the tasks of daily living where some assistance with modification of tasks is necessary.
<b>VERY SEVERELY AFFECTED</b>	

3%	Overall physical activity level severely reduced to around 3%. No travel outside the house is possible. Bed-bound the majority of the day (22+ hours) but may (with difficulty and an exacerbation of symptoms) be able to sit up, walk or be pushed in a wheelchair for very short trips within the home. Nearly all tasks of daily living need to be performed and/or heavily modified by others. Due to problems with swallowing, eating may be very difficult.
1%	Overall physical activity level very severely reduced to around 1%. No travel outside the house is possible. Close to completely bed-bound (lying flat in bed 23.5+ hours a day). May sometimes (with difficulty and with an exacerbation of symptoms) be able to sit up, walk or be pushed in a wheelchair within the home. All tasks of daily living need to be performed and/or very heavily modified by others. Eating and drinking may be very difficult.
<b>PROFOUNDLY SEVERELY AFFECTED</b>	
0.5%	Completely bed-bound and may be unable to turn or move at all. Eating is extremely difficult and liquid food may be necessary (little and often). When swallowing becomes difficult, nasal feeding tubes may be required. Unable to care for ones self at all; bed baths and other personal care that are undertaken by a care-giver may cause a severe relapse in symptoms and/or disease progression and so should not automatically be attempted every day.

## Part 2. Cognitive ability scale

<b>The HFME 3 Part M.E. ability &amp; severity scale</b> <b>PART 2 – COGNITIVE ABILITY SCALE</b>  Copyright Jodi Bassett 2005 to 2010. Taken from <a href="http://www.hfme.org">www.hfme.org</a>	
<b>FULLY RECOVERED</b>	
100%	An unrestricted level of cognitive functioning is possible.
<b>VIRTUALLY RECOVERED</b>	
90%	A high level of cognitive functioning is possible; around 90% of pre-illness level. Able to cope on a cognitive level with full-time study or work without difficulty and enjoy a full social life.
<b>MILDLY AFFECTED</b>	
80%	A high level of cognitive functioning is possible, around 80 - 90%. Minimal restrictions apply for activities that demand a high standard of cognitive functioning. Unable to manage full-time study or work without difficulty in areas that place an excessive demand on a cognitive level.
70%	Cognitive functioning is at/or around 70 - 80%; a daily cognitive activity limit is clearly noted. Unable to work fulltime where high demands are made on a cognitive level, but can work fulltime in less demanding jobs if hours are flexible. Some restrictions on social life.
<b>MODERATELY AFFECTED</b>	
60%	Cognitive functioning is at/or around 60% ; unable to perform tasks which are excessively demanding on a cognitive level, but can complete lighter activities for 5 – 7 hours a day although rest periods are required. Cognitive functioning degenerates significantly in a crowded, noisy or busy environment or with sustained and/or high level use. Social life may be moderately affected.
50%	Cognitive functioning is at/or around 40 -50%; unable to perform tasks which are excessively demanding on a cognitive level, but able to work part-time in lighter activities for 4 - 5 hours a day (or perhaps longer at a reduced quality level) if requirements for quiet and resting are met. Cognitive functioning degenerates significantly in a crowded, noisy or busy environment or with sustained and/or high level use. Social activities with environments that are quiet and not mentally challenging are possible.
<b>MODERATELY TO SEVERELY AFFECTED</b>	

30% Cognitive functioning is reduced to around 30 - 40%; unable to perform mentally challenging tasks, but able to complete simpler cognitive tasks (study or work) for 3 – 4 hours a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration and cognitive ability are significantly affected. Following the plots of some TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

20% Cognitive functioning is reduced to around 20%; unable to perform mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for 2 – 3 hours a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected. Following the plots of TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

#### **SEVERELY AFFECTED**

10% Cognitive functioning is reduced to around 10%; unable to perform mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for 1 – 2 hours a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected at all times and may be severely affected during relapses. Concentration for more than half an hour at a time may be extremely difficult. Following the plots of some TV shows or books may be difficult or impossible. Non-mentally challenging social activities possible on a very restricted basis.

5% Cognitive functioning is reduced to around 5%; unable to perform even moderately mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for about an hour or so each day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected at all times and may be severely affected during relapses. Concentration for more than 10 to 15 minutes at a time may be extremely difficult. Following the plots of TV shows or books may be difficult or impossible. Non-mentally challenging social activities possible occasionally for short periods.

#### **VERY SEVERELY AFFECTED**

3% Cognitive functioning is reduced to less than 5%; able to complete simple cognitive tasks for about 10-30 minutes each day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are severely affected. Concentration may be extremely difficult. Only short periods of TV, radio or reading are possible. A friend can be seen for approximately 10 - 30 minutes a week.

1% May be able to complete simple cognitive tasks such as talking, listening to speech or reading (with difficulty) for several 2–10 minute periods throughout the day if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are very severely affected. Concentration may be extremely difficult. There may be an inability to maintain full consciousness throughout the day. No TV is possible but quiet music or an audio book may be listened to for short periods. A close friend or family member can be seen for a few minutes, occasionally.

#### **PROFOUNDLY SEVERELY AFFECTED**

0.5% Concentration, memory and other cognitive abilities are extremely and severely affected. Achieving even a low level of concentration may be extremely difficult or impossible, and there may be a high degree of cognitive confusion as a result. No TV or radio is possible. There may also be a difficulty maintaining consciousness for more than a few minutes at a time. Receiving visitors (even close family members) is almost impossible or impossible. Talking, reading or writing more than the occasional few words is often impossible.

## Part 3. Symptom severity scale

<b>The HFME 3 Part M.E. ability &amp; severity scale</b> <b>PART 3 – SYMPTOM SEVERITY SCALE</b>	
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<b>Note that symptom severity on a scale of one to ten means:</b>	
<b>Mild Symptoms</b> = 1 to 3. Symptoms present but at so low a level one can forget they are there most of the time.	
<b>Mild/moderate symptoms</b> = 4 to 5	
<b>Moderate symptoms</b> = 6 to 7	
<b>Very Severe Symptoms</b> = 8	
<b>Severe Symptoms</b> = 9	
<b>Extremely severe symptoms</b> = 10. Totally non-functional and also possibly crying out or moaning uncontrollably and/or being near delirium. Completely overwhelmed with pain and suffering. The face muscles may be slack, the body partly or completely paralysed, and thinking or communicating may be impossible. As far as the patient is concerned, being eaten alive by a tiger could not hurt any more, or feel any worse. Absolute agony.	
FULLY RECOVERED	
100%	No symptoms.
VIRTUALLY RECOVERED	
90%	No symptoms at rest. Mild symptoms on occasion following strenuous physical or mental activity but recovery is complete by the next day.
MILDLY AFFECTED	
80%	Mild symptoms (1 to 3) for several hours or days following strenuous physical or mental activity.
70%	Mild symptoms (1 to 3) at rest, worsened to mild/moderate (4 or 5) for several hours or days following strenuous physical or mental activity beyond the person's limits.
MODERATELY AFFECTED	
60%	Mild - mild/moderate symptoms (1 to 5) at rest, worsened to moderate (6 or 7) for several hours or days following physical or mental activity beyond the person's limits.
50%	Mild/moderate symptoms (4 or 5) at rest, consisting of mild/moderate pain and/or sensations of illness/dysfunction throughout the body and brain for some parts of the day, with increasing moderate symptoms (6 or 7) for several hours, days or weeks (or longer) following physical or mental activity beyond the person's limits.
MODERATELY TO SEVERELY AFFECTED	
30%	Moderate symptoms (6 or 7) at rest with moderate pain and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day; increasing moderate (and occasionally severe – level 8) symptoms for several hours, days or weeks or months (or longer) following physical or mental activity beyond the persons limits.
20%	Moderate (6 or 7) and occasionally severe (8) symptoms at rest. There is moderate pain (6 or 7) and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day, increasing to moderate and sometimes severe symptoms for several hours, days, weeks or months (or longer) afterward.
SEVERELY AFFECTED	

10% Moderate to severe symptoms (6–8) at rest. There is moderate to severe pain (6–8) and/or sensations of illness/dysfunction throughout the body and brain for much of the day. Symptoms are severe (8) following any physical or mental activity with a recovery period as low as hours, or as long as days to months, or longer. It is all the person can do to just get through one day at a time.

5% Severe symptoms (8) at rest and following even trivial physical or mental activity with a recovery period of hours or days, or as much as several weeks or months or longer. There is severe pain (8) and/or overwhelming sensations of illness/dysfunction throughout the body and brain for all but a few hours of the day. In some patients only small amounts of stimuli can be tolerated, and only for short periods of time. It is all the person can do to just get through the day a few hours at a time.

**VERY SEVERELY AFFECTED**

3% There is severe pain (8) and/or overwhelming sensations of illness/dysfunction throughout the body and brain for all but a few short periods in the day, increasing to severe or very severe symptoms (8 or 9) following even trivial physical or mental activity with a recovery period of hours days, weeks, months or longer. In some patients only small amounts of stimuli can be tolerated for short periods. It is all the person can do to just get through the day one hour at a time.

1% There is severe pain (8) and/or overwhelming sensations of illness/dysfunction throughout the body and brain almost continually, worsening to very severe (9) or extremely severe (10) following even trivial physical or mental activity with a recovery period of hours, days, weeks or months or longer. In some patients any type of stimulus is intolerable; even very low levels of light, noise, movement or motion are excruciating for more than very short periods. The smallest physical movements bring extreme exacerbations in symptoms. Intellectual activity is similarly affected. It is all the person can do to just get through the day one minute at a time.

**PROFOUNDLY SEVERELY AFFECTED**

0.5% There is very severe (9) pain and/or overwhelming sensations of illness/dysfunction throughout the body and brain *continually*, worsening to extremely severe (10) by even trivial physical or mental activity with a recovery period of hours, days, several weeks or months or longer. In some patients any type of stimulus is intolerable; even very short/low exposures to light, noise, movement and motion are excruciating and may require a long recovery period. The smallest physical movement brings intense exacerbations in symptoms. Mental activity is similarly affected. It is all the person can do to just get through the day one minute or one second at a time.