

3 Part M.E. Ability and Severity Scale

Copyright © by Jodi Bassett, June 2005
Taken from www.ahummingbirdsguide.com



A HUMMINGBIRDS GUIDE TO ME'S	
3 PART M.E. ABILITY & SEVERITY SCALE:	
PART 1 – PHYSICAL ABILITY SCALE	
COMPILED BY JODI BASSETT, 2005. TAKEN FROM WWW.AHUMMINGBIRDSGUIDE.COM	
FULLY RECOVERED	
100 %	An unrestricted (pre-illness) level of physical activity is possible.
VIRTUALLY RECOVERED	
95%	A high level of physical activity is possible, around 95% of pre-illness capabilities. Able to cope physically with full-time study or work without difficulty, plus enjoy a full and active social life.
MILDLY AFFECTED	
90%	A high level of physical activity is possible, around 85 - 95% of expected. Minimal restrictions apply for activities involving exertion only. Able to work full time with difficulty in jobs requiring exertion.
80%	Physical activity is at around 70 - 80% of expected, a daily activity limit is clearly noted. Unable to work full-time in jobs requiring physical exertion, but able to work full-time in lighter activities if hours are flexible. Social activities requiring physical exertion may be difficult.
MODERATELY AFFECTED	
70%	Physical activity is at around 50 - 60% of expected. Unable to perform strenuous tasks without difficulty, but able to work part-time in light activities or deskwork for 5 – 7 hours a day, although rest periods are required. Physical abilities degenerate significantly with sustained exertion.
60%	Physical activity is at around 40 - 50% of expected. Unable to perform strenuous tasks, but able to work part-time in light activities or deskwork for 4 - 5 hours a day if requirements for quiet and resting are met. Physical abilities degenerate significantly with sustained exertion. Physically undemanding social activities are possible.

MODERATE TO SEVERELY AFFECTED

50% Overall activity level reduced to around 30% of expected. May be unable to walk without support much beyond 100/200m, a walking stick or wheelchair may be used to travel longer distances. Several hours of deskwork may be possible each day if requirements for quiet and resting are met. Physically undemanding social activities are possible.

40% Overall physical activity level reduced to around 20% of expected. Not confined to the house but may be unable to walk without support, much beyond 50/100m, 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 in-between.

SEVERELY AFFECTED

30% Overall physical activity level reduced to around 10% of expected. Usually 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 and some assistance with or modification of tasks is often required.

20% Overall physical activity level reduced to around 5% of expected. 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. Bedbound or couch-bound for 21+ hours a day. Activity is restricted almost exclusively to managing the tasks of daily living and some assistance with or modification of tasks is necessary.

VERY SEVERELY AFFECTED

10% Overall physical activity level severely reduced. No travel outside the house is possible. Bedbound 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 short periods/distances interspersed throughout the day (to the bathroom or to travel from room to room). Almost all tasks of daily living need to be done by others and/or heavily modified. Eating may be very difficult.

5% Overall physical activity level very severely reduced. No travel outside the house is possible. Close to completely bedbound (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 for very short periods/distances interspersed throughout the day (to the bathroom or to travel from room to room). All tasks of daily living need to be done by others and/or very heavily modified. Eating and drinking may be very difficult.

EXTREMELY SEVERELY AFFECTED

1% Completely bedbound and may be unable to turn or move in bed (or at all) unassisted. Eating is extremely difficult and liquid food may be necessary (little and often). Swallowing liquids may also be difficult or impossible and in some cases nasal-feeding tubes may be required. Unable to care for oneself at all. Bed-baths (and other personal care tasks) undertaken by a carer or family member may cause severe relapses in symptoms and so only be able to be attempted occasionally.

A HUMMINGBIRDS GUIDE TO ME'S

3 PART M.E. ABILITY & SEVERITY SCALE

PART 2 – COGNITIVE ABILITY SCALE

**COMPILED BY JODI BASSETT, 2005. TAKEN FROM
WWW.AHUMMINGBIRDSGUIDE.COM**

FULLY RECOVERED

100% An unrestricted (pre-illness) level of cognitive functioning is possible.

VIRTUALLY RECOVERED

95% A high level of cognitive functioning is possible, around 95% of what was possible pre-illness. Able to cope on a cognitive level with full-time study or work without difficulty, plus enjoy a full social life.

MILDLY AFFECTED

90% A high level of cognitive functioning is possible, around 85 - 95% of expected. Minimal restrictions apply for activities which demand a high standard of cognitive functioning only. Unable to manage full-time study or work without difficulty in jobs which are excessively demanding on a cognitive level.

80% Cognitive functioning is at around 70 - 80% of expected, a daily cognitive activity limit is clearly noted. Unable to work full-time in jobs that are demanding on a cognitive level, but can work full-time in less demanding jobs if hours are flexible. Some restrictions on social life.

MODERATELY AFFECTED

70% Cognitive functioning is at around 50 - 60% of expected. 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.

60% Cognitive functioning is at around 40 - 50% of expected. 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. Quiet, non-mentally challenging social activities possible.

MODERATE TO SEVERELY AFFECTED

50% Cognitive functioning is reduced to around 30% of expected. 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 TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

40% Cognitive functioning is reduced to around 20% of expected. 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

30% Cognitive functioning is reduced to around 10% of expected. 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 TV shows or books may be difficult or impossible. Non-mentally challenging social activities possible on a very restricted basis.

20% Cognitive functioning is reduced to around 5% of expected. Unable to perform even moderately mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for an hour or so 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 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

10% Cognitive functioning is reduced to less than 5% of expected. Able to complete simple cognitive tasks for 10 – 30 minutes or so 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 severely affected. Concentration may be extremely difficult. Only short periods of TV, radio or reading are possible. A friend can be seen for 10 - 30 minutes once a week or so.

5% 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 friend can be seen for a few minutes.

EXTREMELY SEVERELY AFFECTED

1% Concentration, memory and other cognitive abilities are extremely 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 moments or minutes at a time. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. Reading or writing more than the occasional few words is often impossible.

**3 PART M.E. ABILITY & SEVERITY SCALE
PART 3 – SYMPTOM SEVERITY SCALE**

**COMPILED BY JODI BASSETT, 2005. TAKEN FROM
WWW.AHUMMINGBIRDSGUIDE.COM**

FULLY RECOVERED

100 No symptoms
%

VIRTUALLY RECOVERED

95% No symptoms at rest. Mild symptoms on occasion following strenuous physical or mental activity but recovery is complete by the next day.

MILDLY AFFECTED

90% No symptoms at rest. Mild symptoms (1 – 3/10) for several hours or days following strenuous physical or mental activity.

80% Mild symptoms (1 – 3/10) at rest, worsened to mild/moderate (4 or 5/10) for several hours or days following strenuous physical or mental activity beyond the person's limits.

MODERATELY AFFECTED

70% Mild - mild/moderate symptoms (1 - 5/10) at rest, worsened to moderate (6 or 7/10) for several hours or days following physical or mental activity beyond the person's limits.

60% Mild/moderate symptoms (4 or 5/10) at rest. There is mild/moderate pain and/or sensations of illness/dysfunction throughout the body and brain for some parts of the day. Increasing moderate symptoms (6 or 7/10) for several hours, days or weeks following physical or mental activity beyond the persons limits.

MODERATE TO SEVERELY AFFECTED

50% Moderate symptoms (6 or 7/10) at rest. There is moderate pain and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day. Increasing moderate (and occasionally severe – 8/10) symptoms for several hours, days or weeks following physical or mental activity beyond the persons limits which may persist for hours, days or a week or more afterward.

40% Moderate (6 or 7/10) and occasionally severe (8/10) symptoms at rest. There is moderate pain (6 or 7/10) and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day. Increasing moderate and sometimes severe symptoms for several hours, days or several weeks or more following physical or mental activity beyond the persons limits.

SEVERELY AFFECTED

30% Moderate to severe symptoms (6 – 8/10) at rest. There is moderate to severe pain (6 – 8/10) and/or sensations of illness/dysfunction throughout the body and brain for much of the day. Severe symptoms (8/10) following any physical or mental activity with a recovery period of hours, days or several weeks or months or more. It is all the person can do to just get through one day at a time.

20% Severe symptoms (8/10) at rest and following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. There is severe pain (8/10) 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 stimulus can be tolerated for short periods a few times a day. It is all the person can do to just get through the day a few hours at a time.

VERY SEVERELY AFFECTED

10% There is severe pain (8/10) and/or overwhelming sensations of illness/dysfunction throughout the body and brain for all but a few short periods in the day – worsened to increasing severe or very severe symptoms (8 or 9/10) following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. In some patients only small amounts of stimulus can be tolerated for short periods. It is all the person can do to just get through the day one hour at a time.

5% There is severe pain (8/10) and/or overwhelming sensations of illness/dysfunction throughout the body and brain almost continually - worsened to very severe (9/10) or extremely severe (10/10) following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. In some patients any type of stimulus is intolerable, even very low levels of light, noise, movement and 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.

EXTREMELY SEVERELY AFFECTED

1% There is very severe (9/10) pain and/or overwhelming sensations of illness/dysfunction throughout the body and brain *continually* - worsened to extremely severe (10/10) by even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. 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 movements bring intense exacerbations in symptoms. Mental activity is similarly affected. It is all the person can do to just get through the day one second at a time.

These scales are designed to be used by Myalgic Encephalomyelitis sufferers to measure improvements and changes over different aspects of their illness over time. These scales are not intended for medical use, I am not a medical doctor.

The scale is in three parts because cognitive abilities, physical abilities and symptom severity are often not all be equally affected in each patient. A scale with more than one category should ensure greater accuracy and also hopefully be more encouraging as there is a greater likelihood that you'll score a bit higher in at least one category compared to the other two.

Some suggestions on how you might like to use these scales:

1. Don't forget that if you are somewhere between 30% and 40% (for example), you can rate yourself as somewhere between the two – 35%.
2. You can make charting your progress as simple or as complicated as you like. A simple way to use the scales would be to just write down your scores on each of the three scales along with the date and to keep rating yourself on the scales again every few months. If you'd like a more detailed account you could also:
 - Rate yourself separately for good days and bad days. (eg. On a good day my physical abilities are at 50%, on a bad day I'm at 30%)
 - Few people will find that this or any other chart describes their exact combination of symptoms or experience of the illness perfectly, so you might also like to either modify the chart so that it more fully describes your own symptoms, deleting any bits which don't apply to you and perhaps adding in a few extra bits which do. An easier way to do this might be to just write a few short notes about how you fit in each category (eg. I scored 20% on the cognitive ability scale, but my ability to handle sensory input is at about 10%.)

Terminology used in the scales

Resting: means completely different things at different severity levels. For the mildly ill being at rest may mean watching TV or perhaps sitting in a chair reading a book or having a quiet night in with friends. For the severely ill, these things are not at all restful and indeed would provoke severe relapse.

For the very severely ill, resting means lying down in a dark room, in silence and with no inputs at all (such as TV or radio or light) and not moving at all physically or exerting yourself mentally either. For the very severely ill a better term would be complete incapacitation, rather than 'resting.' The term resting also implies that the inactivity is optional and this is often not the case in the severely ill who are often 'resting' (incapacitated) because it is physically *impossible* for them to do anything else.

For moderately ill patients resting means something somewhere between the two extremes, and so on.

Sensory input: includes light, noise, movement, motion, vibration, odours, touch.

Cognitive abilities: when rating cognitive abilities it is the persons intellectual capabilities which are being referred to, not their state of mental or emotional health which may be at quite a different level altogether.

Symptom severity: on a scale of one to ten means:

Mild symptoms = 1/10 - 3/10

Symptoms present but at so low a level you can just about forget they are there most of the time.

Mild/moderate symptoms = 4/10 – 5/10

Moderate symptoms = 6/10 – 7/10

Severe symptoms = 8/10

Very severe symptoms = 9/10

Extremely severe symptoms = 10/10

As far as you are concerned; being eaten alive by a tiger could NOT hurt any more, or feel any worse than this does, nothing could. Absolute agony.

A note on the percentages given in the scales

As you can see, the different percentages on the scale are not aligned with the exact percentage of a persons ability which remains. ie. Being 30% able does not actually mean you can do 30% of what you could pre-illness etc. The scale was designed this way intentionally for two reasons: 1.

Practicality, and 2. out of consideration for the severely affected. See the [‘ME Ability Scale’](#) page on the website for more information (and a longer explanation).

This text can be downloaded in a printer friendly [Word](#) format, [PDF](#) format or as a [Large-print PDF](#)

Permission is given for this document to be freely redistributed by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author’s attribution) is reproduced in full and without alteration.