

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

The HFME 3 part M.E. ability and severity scale

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3 PART M.E. ABILITY & SEVERITY SCALE: PART 1 – PHYSICAL ABILITY SCALE

FULLY RECOVERED

100% A pre-illness level of physical activity is possible.

VIRTUALLY RECOVERED

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.

MILDLY AFFECTED

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.

MODERATELY AFFECTED

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 observed. Physical abilities degenerate significantly with sustained exertion.

50% Physical activity is at 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.

MODERATELY TO SEVERELY AFFECTED

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'.)

SEVERELY AFFECTED

- 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.

VERY SEVERELY AFFECTED

- 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.

PROFOUNDLY SEVERELY AFFECTED

- 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.

3 PART M.E. ABILITY & SEVERITY SCALE: PART 2 – COGNITIVE ABILITY SCALE**FULLY RECOVERED**

100% An unrestricted level of cognitive functioning is possible.

VIRTUALLY RECOVERED

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.

MILDLY AFFECTED

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.

MODERATELY AFFECTED

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.

MODERATELY TO SEVERELY AFFECTED

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 are 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.

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

0/10 No symptoms

VIRTUALLY RECOVERED

1/10 No symptoms at rest. Mild symptoms on occasion following strenuous physical or mental activity but recovery is complete by the next day.

MILDLY AFFECTED

Note that symptom severity on a scale of one to ten means:

Mild Symptoms = 1 to 3. Symptoms present but at so low a level you can forget they are there most of the time.

Mild/moderate symptoms = 4 to 5

Moderate symptoms = 6 to 7

Very Severe Symptoms = 8

Severe Symptoms = 9

Extremely Severe Symptoms = 10. Totally non-functional. Absolute agony.

2/10 No symptoms at rest. Mild symptoms (1 to 3) for several hours or days following strenuous physical or mental activity.

3/10 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

4/10 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.

5/10 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

6/10 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 person's limits.

7/10 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

8/10 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.

8.5/10 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

9/10 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.

9.5/10 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, 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 exacerbation of 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

10/10 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, 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 exacerbation of 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.

These scales are not intended for medical use and were not created by a medical professional. They are designed to be used by Myalgic Encephalomyelitis (M.E.) sufferers, and perhaps also their carers, to measure improvements and changes in different aspects of the illness over time.

Because physical and cognitive ability and symptom severity are often not equally affected in every patient, this scale is divided into three parts.

A scale with more than one category should ensure greater accuracy and hopefully be more encouraging since there is a great likelihood that patients will score a bit higher in at least one category compared to the other two.

Terminology used in the scales

Resting

Resting means completely different things at different severity levels of illness. For the *mildly ill*, resting may be watching TV or sitting in a chair while reading a book or having a quiet visit with friends. For the *severely ill*, these activities are not at all restful and indeed would provoke relapses.

For the *very severely ill*, resting means lying down in a dark room in silence and with no sensory input at all (TV, radio or light) with zero physical movement or cognitive activity. Clothing must also be comfortable and the room must have a very moderate temperature; not too hot or cold. When referring to resting, a better term for the *very severely ill* would be ‘*complete incapacitation*.’ The term ‘resting’ implies that inactivity is optional; the *severely ill* are often ‘resting’ (i.e. incapacitated) because it is physically impossible for them to do anything else.

For *moderately ill* patients, resting lies somewhere between the above two extremes.

Resting will change according to the severity level of each individual. The *very severely ill* have no symptom-free or safe activity limit. Concepts of pacing or of keeping activity at a level which does not cause immediate or delayed symptoms are useless. Indeed, a sizeable proportion of the *very severely ill* may well be so affected in the first place **because of over-exertion in the early stages of their illness**; they did not know the importance of rest, and in some cases, were not *allowed* to rest adequately. Extremely common in M.E., this is a tragedy and an absolute disgrace.

Severe M.E. restricts life to a degree that healthy people might find hard to imagine, but patients have learned from bitter experience all about the negative consequences of over-exertion. They are reminded on a weekly or daily basis that even with careful control, limits can be misjudged or tasks can take a greater toll than expected. An M.E. patient can never be accused of being too restrictive of her activity levels; she wants to live and experience life as much as possible and has learned to use enormous discipline to avoid over-exertion.

I have never heard of anyone with M.E. who is *too* restrictive with their activity levels; the problem is always the opposite. It is a natural human desire to “keep going” when there are chores waiting to be completed, and for most patients, when there is a moment of feeling somewhat more ‘well,’ it is often less difficult to physically keep pushing themselves (even to the point of worsening the illness) than it is to force themselves to adequately rest. In the earlier stages of the disease (when pushing oneself for short periods is more possible) the patient also often finds it is easier emotionally to forge ahead in physical over-exertion and suffer the consequences rather than stand up to extreme pressure from friends, family and medical staff for these activities to be completed at the same level as in pre-illness..

Resting endlessly for many years is much harder than one can imagine. It has been observed that it is less difficult for a stroke victim to learn to walk and talk again than it is for an M.E. patient to discipline herself to rest endlessly, with no distraction from the chronic pain.

People with M.E. would give anything to be able to work hard to improve their illness, and to be improving every day instead of staying the same or getting worse. The problem of M.E. patients *under-reporting* or *under-estimating* their ability levels just *does not exist*.

This is not about patients being as inactive as possible. A person with moderate M.E. of course does not need to live with the same restrictions as does someone with severe M.E. The point here is just that patients must stay within their individual post-illness limits.

Many M.E. patients try to adhere to the 80% rule. The idea of the 80% rule is for patients to work out how much they can do every day without becoming in any way sicker, and then do only 80% of that. To have each day be the same activity-wise is the goal – without cycles of adrenaline surges and relapses. Avoiding overexertion is essential, but it is not enough. Getting some real rest is important for the M.E. patient too, so that the body has some extra energy and resources to use for healing.

M.E. patients that aren't sure if they are resting enough may try resting significantly more for a week to see which symptoms improve, if any. If symptoms improve then the patient likely needs to cut back activities. Increasing the activity levels of someone with M.E. beyond their individual limits can only be harmful. Gradually increasing activity does not make exercise easier or less damaging; it does not matter how slowly it is done: it has the same harmful effects.

Overexertion

What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress.

The main characteristics of the pattern of symptom exacerbations, relapses and disease progression in M.E. include the following:

- A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50% or less of their pre-illness activity levels.
- B. People with M.E. are limited in how physically active they can be but are also limited in similar ways with cognitive exertion, sensory input and orthostatic stress.

- C. When a person with M.E. is active beyond their individual physical, cognitive, sensory or orthostatic limits, this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
- D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress that is needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient's pre-illness tolerances and abilities.
- E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
- F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
- G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression or death.
- H. The activity limits of M.E. are not short term; an increase in activity levels beyond a patient's individual limits, even if gradual, causes relapse, disease progression or death.
- I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not caused only by overexertion; there is also a base level of illness which can be quite severe even at rest.
- J. Repeated overexertion can harm the patient's chances for future improvement in M.E. Patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
- K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness; this is not the case for very severely affected patients.

Sensory input

Sensory input includes light, noise, movement, motion, vibration, odour and touch.

Cognitive abilities

When rating cognitive abilities it is the person's intellectual capabilities which are being referred to, not their state of mental or emotional health which will most often be at quite a different level altogether.

Symptom severity

Mild Symptoms = 1 to 3. Symptoms present but at so low a level you can forget they are there most of the time.

Mild/moderate symptoms = 4 to 5

Moderate symptoms = 6 to 7

Very Severe Symptoms = 8

Severe Symptoms = 9

Extremely Severe Symptoms = 10. Totally non-functional and/or being near delirium. Completely engulfed in, and overwhelmed with, pain. Absolute agony.

The pain and suffering of M.E. have a number of different 'flavours.' The experience can be made up of severe nausea, vertigo and disequilibrium, cold and hot fevers or feeling both very cold and very hot at the same time, feeling 'poisoned' and very ill, pain in the glands and throat, muscle pain, twitching and uncontrollable spasms, difficulty breathing and breathlessness, cardiac pain and pressure and dysfunction that feels like a heart attack, a feeling of having a heart attack in every organ (caused by lack of blood flow to these organs), sensations of pain and terrible pressure in the brain and behind the eyes, stroke-like or coma-like episodes, abdominal pain and pain/discomfort following meals, seizures and 'sensory storms' (while conscious) and, lastly, an inability to remain conscious for more than a few minutes or hours at a time or for more than a few hours each day in total. Any one of these problems can cause extreme suffering. What makes severe M.E. so terrible is that the patient is almost always dealing with a large number of these problems *all at once*.

For more (fully referenced) information on M.E., see: [What is M.E.?](#) plus [Why patients with severe M.E. are housebound and bedbound](#) and [The importance of avoiding overexertion in M.E.](#) See also: [M.E. vs. M.S.: Similarities and differences](#)

Suggestions on using these scales:

Patients and carers can make charting progress as simple or as complicated as is desired:

- Simple charting: Every few months, write down your (or the patient’s) scores on each of the three scales along with the date.
- Detailed charting: Have a chart that includes “good day” and “bad day” columns, and a notations section, and fill them in accordingly, as shown in the example below.

DATE:	GOOD DAY	BAD DAY	NOTATIONS:
10/10/2011	40% overall with 5/10 symptom severity.		To have days this good I need to rest almost totally for weeks beforehand including avoiding all trips out of the house and any other serious exertions.
10/10/2011		20% 20% 7/10	I scored 20% on the cognitive ability scale and my symptoms are pretty severe.

Few people will find that this or any other chart describes their exact combination of symptoms or experience of the illness, so patients might find that modifying the digital download of the chart enables them to more fully describe their own symptoms.

To read a fully-referenced version of the medical information in this text compiled using information from the world’s leading M.E. experts, please see the ‘What is M.E.?’ the HFME website.

Acknowledgments

Thanks to Roseanne Schoof for editing this paper and for the person with the online pseudonym ‘A rainbow at night’ for making suggestions towards improving this scale.

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Relevant quotes

‘[A] crucial differentiation between M.E. and post viral fatigue syndrome lies in the striking variability of the symptoms not only in the course of a day but often within the hour. This variability of the intensity of the symptoms is not found in post viral fatigue states.’
DR MELVIN RAMSAY



This paper is included in the new *Caring for the M.E. Patient* book by Jodi Bassett.

The book also includes a Foreword by the world’s most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the *HFME Books* page on www.hfme.org

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The HFME ability scale for M.E. patients: Summary

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A form to be filled out by the M.E. patient for the benefit of hospital staff and carers



My name is _____

I have had Myalgic Encephalomyelitis (M.E.) for _____ months/years,
since I was _____ years old.

When I was first ill, I was (circle the correct answer) mildly/moderately affected, moderately affected, moderately/severely affected, severely affected, very severely affected.

I am currently (tick the appropriate box):

MODERATELY AFFECTED

Physical activity is at 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.

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.

Mild/moderate symptoms (4 or 5 out of 10) 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.

MODERATE TO SEVERELY AFFECTED (1)

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.

MODERATE TO SEVERELY AFFECTED (2)

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 no longer considers 'usual'.)

SEVERELY AFFECTED

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.

VERY SEVERELY AFFECTED

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.

EXTREMELY SEVERELY AFFECTED

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.

PROFOUNDLY SEVERELY AFFECTED

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.

Concentration, memory and other cognitive abilities are 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.

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, 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.

Please see the full-length version of this text for more information.

Additional patient notes (if necessary):

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The HFME M.E. ability and severity scale checklist

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M.E. patients may circle the correct number or fill in the blank spaces below.

Name: _____ Date: _____

This checklist refers to my abilities on (1) an average day/week, (2) my worst day/week or (3) my best day/week.

Average time spent upright (standing or sitting) daily: 1 2 3 4 5 6 7 8

KEY: (1) 0 – 5 mins (2) 5 -15 mins (3) 15 - 30 mins (4) 30 - 60 mins (5) 1 - 2 hrs (6) 2 - 3 hrs (7) 4 - 5 hrs (8) 6 - 7 hrs (9) 8 - 10 hrs (10) 12 + hrs

Average time spent on the computer daily: 1 2 3 4 5 6 7 8 9 10

Average time spent with another person or talking on the phone daily: 1 2 3 4 5 6 7 8 9 10

Average time spent reading daily: 1 2 3 4 5 6 7 8 9 10

Average time spent listening to music or audio books daily: 1 2 3 4 5 6 7 8 9 10

Average time spent watching TV daily: 1 2 3 4 5 6 7 8 9 10

Average amount of time high-quality level thinking is possible daily: 1 2 3 4 5 6 7 8 9 10

Average time spent doing housework daily: 1 2 3 4 5 6 7 8 9 10

Average time spent in a total rest state (lying in a darkened quiet room) daily: 1 2 3 4 5 6 7 8 9 10

Ability to eat and drink (ability to use utensils, chew and swallow): (1) I need to be fed entirely by tube (2) very poor (3) poor (4) average (5) good (6) almost always excellent (7) excellent, no problems at all.

Frequency of trips out of the house: (1) housebound for years now (2) housebound for many months now (3) rare (4) once every few months (5) once every 2 – 4 weeks (6) once a week (7) twice weekly (8) 3 – 4 times weekly.

Ability to bathe unassisted: 1 2 3 4 5 6 7 8

KEY: (1) a sponge or bed bath is possible less than once a week (2) a sponge or bed bath is possible once a week (3) a shower or bath is possible once a week so long as the task is modified in certain ways (4) a sponge or bed bath is possible 3 – 5 times weekly (5) a daily sponge or bed bath is possible (6) a bath or shower is possible 3 – 5 times weekly so long as the task is modified in certain ways (7) a daily bath or shower is possible so long as the task is modified in certain ways (8) a daily bath or shower is possible with no problems or restrictions.

Ability to bathe with assistance from a carer: 1 2 3 4 5 6 7 8

Average waking time: _____ am/pm Average time sleep is initiated: _____ am/pm.

Average time spent napping in the daytime: _____

Sleep quality and duration is: (1) appalling (2) very poor (3) poor (4) average (5) good (6) very good (7) excellent.

Sensitivity to noise, rated from 1 to 10, with 10 being extremely severe: 1 2 3 4 5 6 7 8 9 10

Sensitivity to light, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Vertigo and balance problems, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Pain, discomfort and physical suffering, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Nausea, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Sensitivity to (viewing) movement, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Burning eye pain/blurred vision, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

General neurological problems and symptoms, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Severity of cardiac episodes (pain/abnormal function/very low blood pressure), rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

Frequency of severe cardiac episodes, rated from 1 to 10: 1 2 3 4 5 6 7 8 9 10

On average I overexert to the point of a mild-moderate worsening of symptoms and/or adrenaline burst (a hyperactive state caused by the body being put in significant physiological difficulty): (1) every day (2) almost every day (3) every few days (4) once a week (5) once a fortnight (6) every 2 – 3 weeks (7) every 4 – 6 weeks (8) rarely (9) almost never (10) I don't do this at all anymore.

On average I overexert to the point of a moderate-severe worsening of symptoms and/or adrenaline burst (a physiological difficulty caused hyperactive state): 1 2 3 4 5 6 7 8 9 10

The main reasons I overexert myself, if I do, are (circle all that apply): (1) I have no choice, I am not getting any of the care I need to stop my condition deteriorating (2) I need significantly more care than I am getting (3) I need a little bit more care than I am getting (4) I misjudge how able I am to do certain tasks sometimes (5) I need to do some fun things sometimes even though I am too ill for them (6) arguments and heated discussions with some family members (7) dealing with and talking to my carers (8) talking to my friends and family members (9) caring for my children/partner (10) caring for my pets/garden (11) sorting out my finances and other paperwork/responsibilities (12) getting and giving support to my fellow patients (13) I get carried away doing fun tasks sometimes and choose to keep going longer than I should despite the consequences (14) seeking medical care or trying to secure basic welfare (or insurance) entitlements.

My best time of day is _____

My worst is _____

Overall I feel my condition is: (1) at risk of becoming fatal (2) profoundly severe (3) very severe (4) severe (5) moderate/severe (6) moderate (7) mild/moderate (8) mild (9) in an almost complete remission (10) in remission.

Overall I feel my condition is (1) worsening rapidly and terrifyingly (2) worsening slowly (3) stable (4) stable in some ways and improving slowly in some ways (5) uncertain: some parts are worse, some the same and some better (6) improving very slowly in very small ways (7) improving significantly over time (8) improving at an accelerated rate. This is occurring primarily because (leave blank if cause is unknown):

Additional notes (if necessary):

Suggested ways to use the HFME M.E. ability and severity scale checklist

- Patients are advised to print out lots of copies of the checklist, excluding this section, all at once and to fill one out once every 3 - 4 months, or whenever something changes worth making note of. Copies of the checklist can be downloaded free from the HFME website. Any questions that don't apply, just leave blank, or delete from the digital file. Patients may also choose to use only the first page of the checklist.
- When filling in the form, just circle the answers that are most correct and fill in the spaces appropriately OR do this and also write some notes in the margins giving additional information about some or all of the questions.
- This checklist can be used together with the more general HFME 3-part M.E. ability and severity scale, as they each serve slightly different functions.
- Note that the first key included in the form is designed to be used for a number of different questions (to save space), so not all numbered responses will be appropriate for all questions. (It is extremely unlikely that anyone with M.E. would spend 12 hours a day cleaning or on the computer, for example.)

Acknowledgments

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This paper is included in the new *Caring for the M.E. Patient* book by Jodi Bassett.

The book also includes a Foreword by the world's most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the *HFME Books* page on www.hfme.org

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

A one-page summary of the facts of M.E.

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- Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were 'atypical Multiple Sclerosis' and 'atypical Polio.'
- M.E. is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This damage is an essential part of M.E., hence the name M.E. The term M.E. was coined in 1956 and means: my = muscle, algic = pain, encephalo = brain, mye = spinal cord, tis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- M.E. is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- M.E. is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes Polio; an enterovirus.
- M.E. can be more disabling than M.S. or Polio, and many other serious diseases. M.E. is one of the most disabling diseases that exists. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are M.E. patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.
However, the hearts of M.E. patients only barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.
This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (e.g. heart damage or organ failure), disease progression or death.
If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive. *M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*
- M.E. is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- M.E. is a long-term/lifelong neurological disease that affects more than one million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: [What is M.E.? Extra extended version](#). Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.