

Categories of Severity

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 severe 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 too 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 of the level of each individual.

Mild

People with mild CFS/M.E. are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.

Moderate

People with moderate CFS/M.E. have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe

Restricts life to a degree that healthy people might find hard to imagine, but patients have learned from bitter experience all about the extreme negative consequences of over-exertion. They are reminded on a weekly or even 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 his activity levels; he wants to live and experience life as much as possible and has learned to use enormous discipline to avoid over-exertion.

Very Severe

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 too 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.

SYMPTOM SEVERITY SCALE

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 one 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 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.

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

2/10 Mild symptoms 1–3 for several hours, days following strenuous physical or mental activity.

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

MODERATELY AFFECTED

4/10 Mild - mild/moderate symptoms 1–5 at rest, worsened to moderate 6–7 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 6–7 at rest with moderate pain and/or sensations of illness/dysfunction throughout the body & brain for significant periods of the day; increasing moderate & occasionally severe – level 8 symptoms for several hours, days, weeks, months or longer following physical or mental activity beyond limitations.

7/10 Moderate 6–7 with occasional severe 8 symptoms at rest. There is moderate pain 6–7 and/or sensations of illness/dysfunction throughout the body & brain for significant periods of the day, increasing to moderate & severe symptoms for several hours, days, weeks or months (or longer) afterward.

SEVERELY AFFECTED

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

PHYSICAL ABILITY SCALE

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 around 60%: strenuous activities are difficult, limited & regular rest periods are required. Physical abilities degenerate with sustained exertion.

50% Physical activity is 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.

MODERATELY TO SEVERELY AFFECTED

30% Overall activity level reduced to around 30 - 40%. Unable to walk without support beyond 100/200 metres; a walking stick or wheelchair may be used. Several hours of desk work may be possible each day if requirements for quiet and resting are met. Physically undemanding social activities may be possible.

20% Overall physical activity level reduced to around 20%. Not confined to the house, may be unable to walk without support beyond 50/100 metres; a wheelchair may be used to travel longer distances. Requires 3 - 4 rest periods during day;

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. Activity is restricted to managing the tasks of daily living where some assistance is needed & 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.

COGNITIVE ABILITY SCALE

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 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.

Compiled by Wendy Boutilier for Health Canada, Canadian Medical Association Journal (CMAJ)

Canadian Consensus Criteria 2003

<https://www.meao.ca/files/ME-Overview-English.pdf>

International Consensus Criteria 2011

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>

Hummingbird Foundation

<http://www.hfme.org/themeabilityscale.htm>

Global Advocates ME ICC

<https://artzstudios1.wixsite.com/globaladvocatesmeicc>

Dr Ramsay

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1847119/?page=1>

Dr Dowsett & Jane Colby

<https://www.tymestrust.org/pdfs/dowsettcoby.pdf>

Dr Byron Hyde, Nightingale Foundation

<https://www.nightingale.ca/>