

Functional ability scale

100% FULLY RECOVERED

No symptoms, even following physical or mental activity. Able to study (or work) full time without difficulty, and enjoy a social life.

95% VIRTUALLY RECOVERED

No symptoms at rest. Mild symptoms following physical or mental activity – tire rather easily but fully recovered next day. Able to study or work full time without difficulty, but social life is slightly restricted.

90% MILDLY AFFECTED

No symptoms at rest. Mild symptoms following physical or mental activity - tire easily. Study/work full time with some difficulty. Social life rather restricted with gradual recovery over two/three days.

80% MILDY AFFECTED

Mild symptoms at rest, worsened to moderate by physical or mental activity. Full time study at school/college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment. Home tuition or part-time study without difficulty.

70% MODERATELY AFFECTED

Mild symptoms at rest, worsened to severe by physical or mental activity. Daily activity limited. Part time study at school/college is very tiring, and may be restricting social life. Part time work may be possible for a few hours in the day. With careful pacing of activities and rest periods, you may discover windows of time during the day when you feel significantly better. Gentle walking or swimming can be beneficial.

60% MODERATELY AFFECTED

Mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home difficult unless additional support is available (such as use of a wheelchair/quiet room for a rest period). Short (1-2 hours) daily home study/work may be possible on good days. Quiet, non-active social life possible.

50% MODERATE TO SEVERELY AFFECTED

Moderate symptoms at rest. Increasing symptoms following physical or mental activity. Midday rest may still be needed. Simple, short (1hr) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house, but may be unable to walk much beyond 100-200m without support. May manage a trip to the shops in the wheelchair.

40% MODERATE TO SEVERELY AFFECTED

Moderate to severe symptoms following any activity. Care must be taken not to overdo anything at this stage. Not confined to the house, but unable to walk much more than 50-100m, usually requiring aids such as walking stick/crutches. May manage a wheelchair trip to the shops on a quiet day, and 3 or 4 regular rest periods are needed during the day. Only one 'large' activity possible per day – eg. friend dropping by, or doctor's visit, or short home study (half hour at a time), with space usually requiring rest day/s between.

30% SEVERELY AFFECTED

Moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor and home study difficult.

20% SEVERELY AFFECTED

Fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed/settee most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about five to 10 minutes at a time.

10% VERY SEVERELY AFFECTED

Severe symptoms following any activity. Weakness and pain in arms or legs. In bed most of the time but feeling more stable and less dizzy. No travel outside the house. Concentration very difficult indeed. A friend can be seen for ten minutes or so.

5% VERY SEVERELY AFFECTED

Severe symptoms almost continuously, but may be possible to be propped up in bed for very short periods. Weakness and pain in arms or legs can give rise to paralysis; dizziness and nausea. Small, personal care may be possible (e.g. if washing equipment placed on the bed it may be possible to wash some parts of the body). As with 0%, sudden jerking movements can be a problem and what may be described as panic attacks are felt. No TV is possible but a little quiet music or audio book may be listened to for a few minutes. A friend can be seen for a minute for a hug and a few words.

0% VERY SEVERELY AFFECTED

Severe symptoms on a continuous basis. In bed constantly, feeling extremely ill even with permanent rest. Severe dizziness makes it almost impossible to be propped up in bed for longer than a few minutes at a time. Light and noise are very painful to the eyes and ears - curtains are closed and earplugs are needed.

Severe pain almost anywhere in the body with the skin feeling very cold and extremely sensitive to touch. Unable to care for self at all; washing needs to be done a tiny bit at times throughout the day. Nausea and severe fatigue make eating extremely difficult. Liquid based food preferred– little and often. Occasionally, nasal feeding tubes are required when the energy to chew is completely spent.

Any stimulus worsens the feeling of being severely ill, with no movement in the bedroom preferred. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. This is often misread as being "selective mute." Severe adrenaline rushes felt with heightened sensitivity; sleep pattern often completely reversed.