

WORKSHEET 2 – ACTIVITY SCALE FOR SIMPLE ACTIVITY DIARY

Compare today's activity level with the descriptions below. Write the most suitable number in your diary. If you fall between two levels, for instance 40 and 50, you can write the number in between in your diary, 45. Rate today's symptom level on a scale from 0 to 10, where 0 signifies no symptoms, and 10 signifies very severe symptoms. Write this number as well in the diary.

HEALTHY	100 Work or study full time without difficulty, plus enjoy a normal social life and exercise normally. Back to climbing mountains on weekends.
VERY MILD	95 Can manage work or school full time. Social life and a bit of exercise, but have to be careful with physical activity. Somewhat poorer stamina than healthy people.
MILD	90 Considerably better stamina compared to 80%. Can work or study full time, but with some difficulty. Can go out at night without paying dearly for it afterwards, but is still more tired than normal the next day. 80 Can get through the day without problems, so long as one gets sufficient sleep and does not do too much. Full-time work or study is difficult, especially if it is a noisy, crowded or busy environment. Can manage part-time work without difficulty, but need more sleep than before.

<p>MODERATE</p>	<p>70 Can get through the day without a rest break, but need more sleep than healthy people. Daily activity limited. Part-time studying is tiring and may restrict social life. A few hours of part-time work may be possible or working a bit from home. Can manage most household chores and errands with rest afterwards. Have to go to bed early. Can drive short distances. Gentle walking and swimming may be possible.</p> <p>60 Some days a rest break or nap may be necessary. Can get through the day with short rest periods. Daily activity very limited. Can manage housework yourself, but this limits other activities. Can drive short distances. Studying with others or work outside the home is very difficult unless one can get different types of support, such as a wheelchair and a room for rest breaks. One to two hours of studying or work in the home may be possible on good days. Quiet, inactive social life is possible.</p>
<p>MODERATE TO SEVERE</p>	<p>50 Need long rest breaks or need to nap. Short, simple (1 hour) home study possible if alternated with quiet, non-active social life. Limited concentration span. Not confined to the house, but unable to walk far without support (100-200 metres). Can manage a short wheelchair ride, short shopping trips or visit a friend. Midday rest may still be needed. Could manage household tasks with pacing and breaks, but this would mean sacrificing other activities such as education.</p> <p>40 Can be up for 2-3 hours at a stretch, but needs as much rest as activity. Can prepare simple meals and do a little light housework. Not confined to the house, but is rarely able to walk more than 50-100 metres, usually with crutches, stick or rollator. Can manage a short wheelchair ride to the shops on a quiet day. Can drive short distances but prefer others to do the driving. Needs 2-4 regular rest breaks during the day. Can only manage one 'large' activity per day, e.g. friend dropping by or short doctor's visit or half an hour home tuition. Require a resting period of one or more days before the next 'large' activity.</p>

<p>SEVERE</p>	<p>30 Often has a window of 2-3 hours when one can do a bit more, but still needs to rest during this time. Can be up for a while, but cannot move around much. Usually too ill to leave the house, but may be able to manage a short wheelchair ride or a very short walk in the fresh air occasionally. Most of the day resting. Very small activities can be carried out, but homework and home tuition are difficult. Home tuition may be impossible for children at this level. Can do a little light house work, but still needs assistance for many things.</p> <p>20 May be able to get up for an hour or so, but cannot move around much. Usually unable to leave the house. Confined to bed/sofa most of the day, but able to sit up for a few short periods. Unable to concentrate for more than one hour a day in total, but may be able to read for 5-10 minutes at a time. Needs assistance for all housework.</p>
<p>VERY SEVERE</p>	<p>10 In bed all day. Can only be up for a maximum of 10 minutes. No travel outside the home. Concentration very difficult. May be able to manage a visitor for 10 minutes at a time. May occasionally be able to be transported lying down to a test that cannot be done at home, but it takes a long time to get over this afterwards.</p> <p>5 May be able to sit up in bed for very short periods if well supported. Small personal care possible, e.g. it may be possible to wash part of body if washing things are brought to the bed. No TV possible at this stage, but some may be able to cope with a few minutes of quiet music or audio books. A friend can be seen for a minute or so for a hug and a few words.</p> <p>0 In bed constantly and feels extremely ill even with permanent rest. Almost impossible to be propped up in bed for more than a few minutes. Curtains must be closed and ear plugs are necessary. Unable to care for yourself. Washing has to be done a tiny bit at a time. Eating is extremely difficult. Liquid feed preferred at this stage, little and often. Sometimes nasal feeding tubes are necessary when energy to chew is completely spent. Other people moving around the room is straining. Visitors almost impossible. Speaking is often impossible even to the carer or family. This may be misunderstood as being selectively mute.</p>

This functional ability guide is only meant as a guide. There will always be individual differences. The activities mentioned at each level are only examples.

The scale is a combination and adaptation of two scales, ‘Association of Young People with ME’s Functional Ability Scale’ and the scale in the first edition of *Chronic Fatigue Syndrome – A Treatment Guide* by Lauren M. Gellman and Erica F. Verillo. In the original version both describe ability level and symptom level in one, and both scales assume that people with a high ability level have a low symptom level and vice versa. This means that the scales do not cover all possible variations. For instance, it is possible to do a lot in one day and feel very ill whilst doing it, or do very little and feel relatively okay. To register these nuances one has to assess ability level and symptom level in two separate scales. That is why Chapter 14 recommends that one assesses the symptom level from 0 to 10, but uses the above scale when assessing the activity level. For this reason, I have removed the symptom level in this version of the scale.