# Adapting mindfulness courses to the needs of people with MS

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## Introduction

People affected by multiple sclerosis (MS) are faced with uncertainty about the future; unpleasant and unpredictable symptoms, treatment regimens and drug side effects. People with MS have been found to exhibit a higher prevalence of mood disorders compared to individuals with other chronic medical[1] or neurological[2] conditions. The prevalence rate for depression in MS is 18.5% and for anxiety 44.5%[3]. Despite a number of upsetting and debilitating challenges, many people respond in ways that mean they can maintain an acceptable, or good, quality of life[4, 5]. Supporting people who have difficulties adjusting to MS challenges is important.

Mindfulness based group therapy can help people adjust to chronic illness and manage unpleasant symptoms. Acceptance is a key component of mindfulness courses. Acceptance may also be particularly important in the context of progressive illness where there is little, if anything, that can be done to halt deterioration. Mindfulness teaches us to relate to our thoughts and to accept them as passing events that do not necessarily represent reality[6]. Mindfulness is based on the philosophy that human suffering develops in part by efforts to struggle with, and avoid, our own psychological and emotional pain. Changing our relationship to thoughts can lead to less suffering.

## Mindfulness for health

Mindfulness is an increasingly popular and effective way to help people relate to their thoughts and emotions in a different way. Mindfulness teaches us to make peace with our thoughts and emotions rather than try to change them or ignore them. Research findings show that mindfulness courses reduce depression and anxiety and increase health related quality of life in people with a range of medical conditions[7].

During a mindfulness practice, we sit upright and focus on something straightforward, like the in- and out-flow of breath. We aim to nurture a curiosity about these sensations – not to explain them or change them, but to know them. Over a typical eight-week course participants complete a substantial amount of mindfulness practice (45 mins CD guided meditation daily) and participate in weekly group sessions (2-2.5 hours long), where they discuss and reflect on their practice.

## MS and mindfulness

MS can have profound consequences including disruption of life goals, employment, income, relationships, social and leisure activities of daily living. Therefore, it is not surprising that it poses multiple challenges for psychological adjustment. Even though a lot of people manage to adjust to MS in a positive way, others face difficulties.

A recent systematic review identified three controlled trials on mindfulness in MS[8]. After the eight-week course, people affected by MS showed improvements in MS quality of life, depression and fatigue[9], improvements in standing balance[10], and reductions in fatigue and pain[11]. These results suggest that mindfulness may be helpful in reducing psychological distress and helping with MS symptom management.

Mindfulness meditation practice requires continuous attention and the ability to sit still in one position. For people affected by MS these requirements may be more challenging and we need to take into consideration compromised concentration, fatigue and possible problems with sitting in one posture. We can maximize the effects of mindfulness courses by adapting them to accommodate the specific needs of people with MS. In this way, mindfulness courses can not only be more relevant, but also more accessible, to people with different degrees of disease severity and disability. There are a few aspects of the eight-week mindfulness courses that could be adapted.

Firstly, meditation practice in sessions and at home can be shortened to 10-20 minutes, rather than the traditional 45 minutes. Studies that examined the effectiveness of mindfulness courses, while using shorter mindfulness practices, have been successful before[12, 13]. The shorter length of the homework practice can make the course more attractive and people may find it easier to keep up their daily practice.

Secondly, mindfulness sessions include a mixture of group mindfulness practices and discussions. These activities require a lot of focused attention, reflection and interaction with other participants and the facilitator to reach insights. The length of the sessions can make them difficult to follow, and the traditional 2.5 hours sessions may be prohibitive for people with MS, as fatigue is a frequent symptom. Sessions with a shorter duration might be a

better alternative, for example one hour sessions that retain the original structure and purposes, for people affected by MS. Given that no dose response has been found between in-class hours and effect size[14], this change is unlikely to compromise the effectiveness of the course.

Thirdly, face-to-face group interventions, although ideal to create a supportive environment for the mindfulness practices, exclude not only those in rural areas but also many of those most severely affected by the condition, who may have the most to gain. Therefore, alternative ways to deliver the course remotely, for example via video-conferences, are worth considering. There has been increasing use of distance delivered interventions for people with disease related barriers as technology has advanced[15]. Encouraging findings have been reported using tele-conferences to deliver mindfulness intervention with people who experience both epilepsy and depression[13]. Thus distance delivered interventions can be a useful tool in order to make potentially beneficial interventions more accessible[16, 17]. Skype is a free online software, which allows callers to see one another, and can involve a group of people. The visual and audio contact would make rapport with the facilitator and other group members easier than in tele-conferences and therefore can be a good alternative to face-to-face group format.

Finally, in the CD instructions the facilitators need to give more details on MS specific sensations including painful sensations, lack of sensation or difficulties retaining posture. As mobility is an issue for people with MS, mindful movement and mindful walking practices that are included in the original mindfulness based interventions might not be appropriate.

# Conclusion

The traditional way that mindfulness courses are delivered can be prohibitive for people who may struggle with concentration, fatigue and other physical constraints. Reducing the length of the meditation practices and the weekly sessions, and also finding alternative ways to deliver the course, can make mindfulness easier to access and easier to follow through with.

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