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**Title:**

# Developing Recommendations for Adapted Mindfulness-based Practices for People with Neurological Impairment or Injury: The SMALL PROMPTS Approach

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# Developing Recommendations for Adapted Mindfulness-based Practices for People with Neurological Impairment or Injury: The SMALL PROMPTS Approach

Abstract (250 words):

Objectives: Standardised Mindfulness-based Interventions (MBIs), used for the management of physical and psychological symptoms associated with neurological impairment/injury (NI), have been problematised as lacking accessibility due to their focus on sensory presence and mindful walking. Research is needed to generate formalised recommendations regarding how MBIs may be best adapted to enhance their suitability for people with NI.

Methods: A two-phase qualitative study was completed. Firstly, semi-structured interviews were undertaken with eight accredited Mindfulness Teachers with NI. Interviews reviewed the adaptations participants made in their personal and teaching practice, using Thematic Analysis, and generated recommendations for adaptations to MBIs specific to people with NI. Secondly, using the DELPHI method, the adapted practice recommendations were reviewed and revised via three rounds, following cognitive interviews with an expert panel (N=5 trained mindfulness teachers with NI).

Results: Ten core areas for adaptation are proposed and validated, acting as SMALL PROMPTS which can be used to adapt mindfulness-based teaching techniques to the specific requirements of people with NI: (1) Skin/bladder/bowel management; (2) *Mindful movement*; (3) *Accessible training*; (4) *Language Leadership*; (5) *Permissive pRactice*; (6) *Optimising timelines*; (7) *Management of posture*; (8) Inclusion of Pacing; (9) *Teaching from experience;* and (10) *Body Scanning*.

Conclusions: Mindfulness is a highly applicable approach for people with sensory loss, however significant, specific adaptations are required to improve inclusivity and accessibility. The SMALL PROMPTS adaptations increase the accessibility, applicability and utility of MBIs for populations living with NI, enhancing effective management of physical and psychological wellbeing and optimising MBI delivery.

Keywords: Spinal Cord Injury, Functional Neurological Disorder, Multiple Sclerosis, Accessibility, Disability, Wheelchair, Meditation

## Introduction

Living with neurological injury or impairment (NI) because of a medical condition which alters sensory or neurological processing, can present significant physical and psychological challenges. Such challenges are typically multifactorial and have demonstrated that mental health concerns are persistently elevated in populations where NI has occurred (Aaby et al., 2020). Prevalence rates suggest that living with a neurological condition represents a greater risk factor for poor mental health than in other chronic health conditions: there is a 1.29-fold increased risk of anxiety or depression after spinal cord injury (SCI) when compared against prevalence rates in other chronic health conditions (Lim et al., 2017). In Multiple Sclerosis (MS), lifetime prevalence rates for depression are even higher, at around 50% (Patten et al., 2017), with anxiety rates further elevated, ranging between 43% and 70% (Boeschoten et al., 2017).

Interventions to support mental health in populations with NI, are fundamental to improving quality of life (Lo et al., 2021), reducing early mortality, suicidal ideation and further psychiatric comorbidities (McCullumsmith et al., 2015). Yet interventions for populations with NI may need adaptation and tailoring to account for the specific needs of the population and to optimise mental health outcomes (Capron et al., 2020). It may not be adequate simply to administer standardised interventions to a population with, for example, traumatic SCI or progressive MS; indeed doing so may risk exacerbating treatment-related risk factors such as perceptions of difference and disability, heightened awareness of symptoms and psychological distress (Finlay et al., 2021). There is an urgent need, therefore, to clarify where specific adaptations accounting for NI and sensory loss should be made to standardised mental health and physical health treatment interventions.

Research has demonstrated that people with NI are keen to explore psychological interventions by which they can proactively engage in self-management of their health (Hearn et al., 2015). As such, mindfulness-based interventions (MBIs) have been implicated as a viable target for use with people living with NI (Hearn & Finlay, 2018). Indeed, MBIs improve mental health and quality of life in people with MS (Blankespoor et al., 2017; Simpson et al., 2017; Ulrichsen et al., 2016) and SCI (Hearn & Finlay, 2018; Skinner et al., 2010), and are recommended for consideration with Functional Neurological Disorder (FND; LaFaver et al., 2020). Certainly, wider research with other chronic health populations shows promising results: MBIs have been found to improve pain management (Bawa et al., 2015), reduce psychological distress (Pearson et al., 2018), and enhance resilience (Nila et al., 2016). They also function to increase self-protective awareness of early physical symptoms and increase proactive condition self-management and autonomy (reference blinded for peer review). However, specific to populations with NI, previous research highlights significant physical and psychological barriers associated with realizing mindfulness-based practices; barriers which have, as yet, not been fully addressed (Hearn et al., 2020; Simpson et al., 2019). Resolving such barriers to the use of mindfulness experienced by populations with NI, would improve parity in care delivery and, ensure that an intervention approach that shows promise for supporting mental health after SCI and MS, is appropriately tailored to such population needs.

The barriers identified in previous research are multi-factorial. Physically, concerns about the utility of MBIs for NI surround: (i) the difficulty of undertaking body scans when sensation is not present (Finlay et al., 2021); (ii) perceived expectations of supine meditation (Simpson et al., 2019); (iii) ‘mindful walking’ as a central tenet of standardised MBIs (Kabat-Zinn, 2013;

Simpson et al., 2019), something which is not always achievable after NI; and (iv) the lack of standardised adapted mindfulness practices for wheelchair users and/or those with NI. Psychologically, evidence suggests that the formulation of MBIs for neurological disability needs careful consideration as it may risk: (i) (re-)activating grief processes associated with traumatic injury or chronic illness diagnosis ([reference blinded for review]), (ii) heightening awareness of, and distress associated with, sensory loss, particularly in the short-term (Hearn et al., 2020); and (iii) overtly rely upon sensation-focused language which may exacerbate perceptions of mindfulness being non-inclusive and inaccessible for populations living with NI ([reference blinded for review]). These are all elements which may contribute to concern about the suitability and adaptability of MBIs for SCI/MS.

Consequently, there is an urgent need to develop formal recommendations by which mindfulness-based practices may be best adapted for use in populations with NI. The current study aimed to generate clinical recommendations to highlight priority adaptations to mindfulness teaching for populations with sensory loss (see also [three references, blinded for review]). To do so, experienced mindfulness practitioners/teachers with sensory impairment because of SCI, MS or FND, were interviewed to review the specific and skills-based adaptations they would recommend for enhancing the accessibility of MBIs for the target population. Additionally, expert panels were formed to review the proposed adaptations through cognitive interviews. This research therefore aimed to elicit the core recommendations proposed for adapting mindfulness-based practices for populations with NI, and to review those recommendations in full to develop guidelines for best practice.

## Methods

### *Design*

A three-stage modified DELPHI method was used (Coulter et al., 2016; de Meyrick, 2003): Phase 1 was undertaken between between May 2018 and September 2019, and Phases 2 and 3 between January 2021 and June 2021. The DELPHI method is an iterative method for developing consensus of expert opinions (de Meyrick, 2003) and has been previously applied to health and psychological research including recently the application of mindfulness-based cognitive therapy (Williams et al., 2021). In the present DELPHI Study design, an a priori criterion of three rounds was set (following Trevelyan & Robinson, 2015): Round 1 consisted of a qualitative interview design employing a semi-structured interview schedule, whereby data was analysed inductively using thematic analysis (Braun & Clarke, 2021) to develop recommendations for adapted practice. Round 2 comprised cognitive interviews with five expert panellists who reviewed the consensus, scored and amended recommendations. Finally, in Round 3 the modified practice recommendations were re-reviewed by the expert panellists, re-rated and final amendments made accordingly (see Figure 1).

### *Participants and Recruitment*

*Round 1: Interviews*: Participants were purposively sampled from a database of qualified mindfulness teachers maintained by Breathworks as a National Registry of Mindfulness Teachers. Inclusion criteria included registered Mindfulness teachers who were: qualified to teach Mindfulness for Health courses, teaching three or more mindfulness courses per year, maintaining an active personal mindfulness practice, and had a clinical diagnosis of SCI, MS or FND. Due to the specific nature of the participants needed for this study, participants were

additionally asked to contact other mindfulness teachers who met the inclusion criteria but who were outside of the database, using snowball sampling (Noy, 2008).

Eight participants met the inclusion criteria for the current study (five females, three males; mean age 52 years (SD = 9.5 years). Six participants had SCI, one had been diagnosed with FND affecting mobility and sensation and one with MS. Participant demographic characteristics are shown in Table 1. The unique characteristics of the sampled population mean that the sample size is modest but represents, to the best of our knowledge, all possible members of the Breathworks National Registry who met the inclusion criteria at the time of Phase 1 recruitment over a sixteen-month recruitment period (May 2018-September 2019). The recruitment therefore has achieved sampling adequacy and met pragmatic constraints on further sampling (Vasileiou et al., 2018).

*Rounds 2 and 3: Expert Panelists*: A subgroup of five (3 male, 2 female) of the mindfulness teachers interviewed in Round 1 (above) were invited as expert panellists to review proposed recommendations for adapted practice. All experts had personal teaching experience of more than ten years and clinical oversight/supervision of trainee mindfulness practitioners. All expert panellists were retained in Rounds 2 and 3.

*Materials*

*Demographics Questionnaire*: Brief medical history, approximate date of diagnosis of SCI/MS/FND, teaching experience, teacher training qualifications completed, and regularity and duration of personal mindfulness practice were recorded at the time of Round 1 interviews.

*Round 1: Interview Schedule*: A semi-structured interview schedule was developed encompassing two domains: (1) experiential factors associated with personal use of mindfulness practice when living with SCI/MS/FND (previously reported in [two published papers, blinded for review]); and (2) perspectives on teaching mindfulness when living with SCI/MS/FND, as reported here. Following in-depth literature scoping, the interview schedule was developed, informed by previous published research highlighting the barriers to people with SCI using mindfulness ([two published papers blinded for review; Hearn et al., 2020), in conjunction with a patient representative with SCI. Questions were deliberately left broad to facilitate open discussion and allow the interviewee to direct their answers to factors that they felt were of primary importance for them (Newcomer et al., 2015). The four interview questions on teaching were designed to specifically probe the decision and desire to train as a mindfulness teacher, adaptations to teaching that enabled the teachers to account for variability in sensory proprioception and recommendations for an adapted mindfulness programme.

*Round 2: Cognitive Interviews for Adapted Practice Recommendations*: Individual deductive cognitive interviews were designed for the expert panel, following guidelines by Willis (2015), eliciting verbal feedback on each item in the adapted practice recommendations (domains and statements). A 5-point Likert scale was also used by participants/panellists to score each recommendation for adaptation on (a) clarity of wording and (b) relevance to NI using the end-points 0 = not at all clear/relevant and 5 = extremely clear/relevant.

*Round 3: Re-rating and Consensus*: Expert panelists were presented with the final recommendations table, their own scores and the scores and comments of their colleagues and were invited to adjust their ratings/comment using the measures of relevance/clarity as described above.

*Procedure*

Ethical approval was granted by the [blinded for review] School of Psychology and Wellbeing Ethics Committee. Participants were recruited from the Breathworks Registry by providing details about the study and recruitment in their newsletter and web forum. Interested participants were provided with an information sheet and consent form via email and were asked to return their demographic questionnaires, signed consent forms and then to schedule an interview online if they were interested in continuing with the research.

*Round 1: Semi-structured interviews:* The semi-structured interviews were conducted by the first author (N = 3) or by trainee health psychologists (N = 5). All interviewers had undertaken intensive training in interview and research methods along with further training specific to this project (peer-reviewed role plays and fidelity checks). All interviews were audio-recorded and lasted from 50-93 minutes (mean duration 63.5±16.9 minutes), therefore met recommendations for individual semi-structured interviews in qualitative research (DiCicco-Bloom & Crabtree, 2006). Participants were thanked and debriefed at the end of their interviews. Interviews were transcribed verbatim and anonymised with all identifying features/names changed and pseudonyms applied. Each participant's own transcript was returned to them so that they were able to clarify any thoughts that they felt had not been fully expressed and, additionally, to add any further information they felt might be relevant,

following recommendations of 'member checking' (Birt et al., 2016). No participant chose to add further information, though two participants provided clarification to minor points of discussion within the transcript but made no substantial edits or changes to thematic content.

*Round 2: Review of adapted practice recommendations*: Cognitive interviews with the expert panel were undertaken individually and ranged from 32 to 60 minutes in length (mean duration 50.1±12.55 minutes). Interviewees were reminded of the purpose of the cognitive interviews (to review the adapted practice recommendations), and were provided with the adapted practice table, which was then sequentially reviewed through open discussion, in accordance with the guidelines for cognitive interviews by Willis (2015). Each item in the table was additionally scored for clarity and relevance (for people with NI).

*Round 3: Re-review of amended adapted practice recommendations*: Expert panel members were provided with the amended table, their own scores and the scores/comments from the other panellists and were asked whether they would make any further amendments or changes to their scores. Expert panel representatives were thanked for participation and debriefed in full.

*Data Analysis*

*Round 1: Interviews*: Demographic data were analysed using descriptive statistics (means and standard deviations). Thematic Analysis was conducted inductively by [initials blinded for review] and [initials blinded for review], following Braun and Clarke's (2006) six phases: (1) familiarisation with the data; (2) coding; (3) generating intial themes; (4) developing and reviewing themes; (5) refining, defining, and naming the themes; and (6) writing up.

Recurrent themes were discussed within the research team and were returned to all participants for further comment. Inter-rater reliability was assessed using 100% of the transcripts. Disagreement over domains was resolved through discussion in close consultation with the transcripts and thematic coding framework and in collaboration with the last author [initials blinded for review]. A first iteration of the adaptated practice recommendations table was then prepared, based on the thematic findings.

*Round 2: Adapted Practice Recommendations:* Results from the expert cognitive interviews were analysed in accordance with recommendations by Willis (2015), adapted to account for the fact that their assessment was of a recommendations table rather than a new outcome measure. Analyses therefore analysed response rate (n, %) and Likert-scale items were anlaysed via means (standard deviations). Consensus agreement was calculated based on the quantitative analyses of clarity and relevance (for people with NI). Recommendation table items scoring less than 4 (of 5) were revised in full. All feedback comments were reviewed and revised into succinct statements to create the final draft reviewed in Round 3.

*Round 3: Finalised adapted practice recommendations:* After returning the amended table to participants with the full comments from all panelists, participants were given the option to amend their scores and provide further feedback on table items for recommended practice. Consensus agreement was re-calculated and round 3 verbatim responses were either categorised as 'endorsed' (determined as a positive participant response with wording such as 'agree' or 'no comment' or 'unendorsed', such as if removal of the item was recommended. The final recommendations table was then prepared by the research team.

## Results

### *Round 1: Recommendations Development and Theme Generation*

Inductive thematic analysis led to the identification of nine themes which highlighted core adaptations recommended for improving the practice and teaching of mindfulness for people with sensory loss and neurological injury/impairment: (1) Physical care of s*kin/bladder/bowel management*; (2) *Mindful movement*; (3) *Accessible training*; (4) *Language leadership;* (5) *Flexibility through permissive practice*; (6) *Optimising timelines*; (7) *Management of posture*; (8) Inclusion of pacing; and (9) *Teaching from experience*. One further theme pertaining to *Body Scanning* and further detail on *Language Leadership* have been presented separately in two publications (references blinded for peer review) and domains and recommendations statements pertaining to these themes were therefore included in Rounds 2 and 3.

### *Theme 1: Physical care of skin, bladder and bowel*

The initial theme for adaptation referred to physical considerations that accompany skin, bladder and bowel management. Participants referenced consideration of catheterisation, comfort breaks and session timing to account for the challenges of bladder and bowel management: “I always have to work backwards because I’ve got my bowel management routine, which is really time consuming, as it is for many people” (Sarah). Expressing this clearly, Keith highlighted the need to allow people to respond dynamically to their bladder and bowel needs *during* teaching sessions: “if your bladder begins to fill up you can go autonomic [autonomic dysreflexia]. I start to get a headache, I flush. So, just knowing that if that happens, then go up to the toilet. You don't have to stay” (Keith). To reduce the likelihood of pressure sores, quality monitoring of postural aids needs to be undertaken:

> I suppose one of the things that is also making sure that you're not going to develop a pressure sore from sitting for an hour on a cushion. In the past, I would get off my butt, lie down or whatever to get off my backside so that the pressure is getting relieved. So that's just quite a practical thing. Like some of the meditation cushions that you get have got little husks in them. So, I'm not very comfortable about using them in case the pointy bit creates a pressure sore. But also, to get back up, I need to push down on the cushion, so I use a cushion made of cotton wadding that's full of compressed cotton. Posture should be important. (Keith)

Mindfulness instructors working with populations with sensory impairment therefore need to consider the practicalities of skin, bladder, and bowel management.

*Theme 2: Mindful movement*

All mindfulness teachers in the current study expressed concern about the term 'mindful walking' and preferred the use of mindful movement, experiencing 'mindful walking' to be non-inclusive:

> Well, some of the mindfulness practices that people do, I can't do. So, a lot of people do a mindful walking practice. And then I thought, well, I can't. I thought way back, 'well, I can't do that because I can't walk'. Then I realized that it was just mindfully moving. So, for me, it became mindfully wheeling around. (Simon)

Indeed, significant care was recommended over the use of mindful movement to avoid perceptions of exclusion:

> I mean obviously I wouldn't want to take people through a whole range of yoga moves. That's gonna be impossible. So, the mindful movement would be erm, well, certain elements would be avoided and then I'd bring in other elements that would

> be adapted to make the use of using a wheelchair or whatever action, whatever motion people have. Yeah, just to accommodate them and to make sure that they're not feeling like they're excluded because of their disability and really being aware of making sure that doesn't happen. (Robert)

The concept of using a wheelchair for mindful wheeling was strong across all interviews, and further explanation about how that could be experienced in greater depth was given:

> [I] notice the different textures that my chair is wheeling over, and how that felt in my body or how it was reacting and responded to that and just the feeling of my body really kind of sinking down into my chair and identifying where the points of contact were (Jade)

Robert expanded the idea of mindful movement further, to account for instances when movement is not possible. As advocated by the majority of participants, he recommended using visualisation techniques if movement was not appropriate:

> I mean it's not novel, it's quite a kind of standard approach to invite anybody that can't move a particular part of their body for whatever reason to imagine that limb moving or movement in the certain part of the body. So, working with that as well. (Robert)

Therefore, mindful movement, achieved either through use of wheelchairs or by visualisation, was considered an adaptive method of responding to NI.

*Theme 3: Accessible training*

If using mindful movement within programmes, the physical accessibility of the venue was a primary consideration and repeatedly discussed by all participants: "one of the prime things that I have a problem with. Well not a problem, but I've got to deal with it, is finding a venue

that really works for me. And facilities in the venue as well" (Robert; Lines 401-407). Keith specifically recommended the use of larger rooms to allow for multiple wheelchair users: "So the space itself will need to be spacious".

In contrast to the discussions of physical venue accessibility, participants argued for the value of online mindfulness programmes for people with SCI/MS/FND:

> Because for some people face-to-face would be amazing. Say they're on the ward for months and there's a weekly class that they can go to with other people in a room, building connection, that would be really good, but for it to have an online option as well. So that the people who are stuck at home, who can't get out, can access it. (Sarah)

Jenny agreed and felt that online accessibility would be positively received: "I think with a spinal cord injury, being in your own home when you're being introduced to something new is actually probably a really positive way of doing it." Given the potential for restricted function, however, Sarah recommended that inclusive technology should be considered if an online medium were to be used: "maybe people with no hand function, they could make a video recording so people could feel really included. So, you'd want to use inclusive technology" (Sarah). Through careful consideration of physical space requirements, the viability of online delivery and/or adaptive technology, participants felt that mindfulness could be more inclusive to account for the physical needs of prospective participants.

*Theme 4: Language leadership*

Participants felt that prioritising inclusive language was paramount for ensuring that training was fully accessible. Inclusive language was considered to be multidimensional, requiring

both person-centred word choices and, more broadly, a careful selection of teaching terminology when explaining mindfulness-based practices such that sensory presence and absence were presented equally. For example, use language that avoids jargon or condition-based labels: “Definitely don’t speak at people. Say if you were doing it with ‘paraplegics’ or ‘disabled’ people. Really relate to them as people, not as patients. And the language that you use; maybe avoid medical language, completely.” (Keith). Then also to encompass sensory absence and sensory presence within mindfulness practice instructions:

> One could do it in a way that it’s multipurpose so you do something like ‘now we’re going to be aware of our feet, if you have sensations in your feet, what sensations are present? If you haven’t got any sensations, how are you aware of the absence of sensations? How is that showing up?’ Something like that.” (Sarah)

Accessible language was felt by participants to provide an atmosphere in which mindfulness-based practices could be safely and sensitively explored by people with NI.

*Theme 5: Flexibility through permissive practice*

This theme highlighted the importance of formulating a flexible mindfulness programme which encompasses the specific needs of the group, in accordance with their medical condition(s). This principally involved a greater degree of malleability in the way in which practices were applied, such that all could access these practices:

> A lot of people are taught to use a set programme, and some of them are even scripted. I think that’s just bonkers. You really need to be able to do a formulation for everyone you’re working with. So, I will always assess the

> group and make a formulation for the group and make sure that all the practices I do, everybody will be able to do. And not just go in and just do a programme and assume everyone can do the same thing. (Tricia)

This appreciation for flexibility was expressed within teaching as a need for gentleness and permissiveness: "the way I lead it is very, very gentle so that's another thing about I would say the way I've developed as a teacher because of the spinal injury. Everything we're teaching, everything is very, very gentle. And very permissive" (Sarah). In communicating permissive flexibility within teaching sessions, it was considered beneficial to teach about the different stances:

> I would include saying that there's four different sort of mindful states: standing, sitting, lying and walking [movement]. So, I would say to people, 'if you can't sit, that's ok'. 'If you have to lie down, that's fine'. It's not a rigid fit that you have to sit down for meditation. I want people to know that it's open. (Pete)

This theme demonstrates the need to encourage and give permission for variation within the assessment of which mindfulness techniques to use in the formulation of the mindfulness-based intervention programme and delivery. Importantly, there is a need to educate participants about the adaptations that can be made, ultimately guiding them towards autonomous tailoring of practice which is responsive to their unique health needs.

*Theme 6: Optimising timelines*

Participants explored the length of mindfulness sessions and practices. Sarah argued for a reduced course length due to the physical health demands that participants would already be living with:

> I think with people with chronic health conditions, it's demanding. So, people might find that you say an eight-week course where it's two-and-a-half-hours a week that can just be too much for some people. Just physically too demanding. (Sarah)

Consequently, she recommended that the mindfulness practitioner would focus on the learning outcomes of the programme and ensure that timelines were malleable to account for the context in which it would be delivered:

> I'd probably come up with something that's a little bit flexible in terms of how long the sessions are. So, you'd have key components that you want to communicate each week. And if someone's got two hours on the ward, they could do it in two hours and if someone's got one hour they could do it in one hour. So, I'd keep it flexible, not too rigid and I'd have 'what's the key point at each session that we're trying to get across'. (Sarah)

Collectively, all participants argued that the optimum weekly timeline should be reduced from the 2.5 hours typically employed in Mindfulness for Health Programmes:

> At the moment, the health course is two and a half hours, sometimes three hours a week and it's too long. [Do] two hours a week. And within the two hours, half an hour break. I think a tea breaks are good, because I think the social aspect of these courses is brilliant. Definitely. So, an hour for learning, then it's half an hour tea and coffee. Because people can chat to each other, making friends and stuff. Because chronic health conditions are lonely, we don't get out much, ok, so I think it's very important. (Pete)

Keith was confirmatory: "I just thought if you are doing like a weekly session, you could do an hour and a half, that would be long enough, I would imagine, for most people" (Keith).

More broadly, the concept of reducing timelines was also extended to the length of meditation practices:

> I think most people with FND would respond much better to beginning with short practices. I think because of fatigue and sometimes poor concentration, and also that feeling of if it feels a bit overwhelming to begin with, knowing that it's just a short practice to tap into it to learn some of the techniques. (Jade)

This theme demonstrated that, where possible, efficient use of shorter timelines should be prioritised, such that the number and length of weekly sessions and timings for meditations should be reduced in order to accommodate the physical demands of living with a neurological condition.

*Theme 7: Management of Posture*

As a result of SCI/MS/FND, posture is a primary target for consideration if mindfulness is to be found comfortable. Participants need to be supported in changing their posture, with adequate postural aids provided:

> Something about posture I think would need to be done. Because I think if you are sitting in an uncomfortable posture and somebody asks you to be mindful, it's just gonna be unpleasant. So, it might well be you get people to lay down in semi-supine position and then that introduces all sorts of other [challenges]. Having lots of helpers [is needed]. (Keith)

All participants referenced that practices which are based on the floor need further consideration and awareness:

> You can't just get them down on the floor that easy. If it's getting on the floor, it's very difficult for me and them to get back up. OK, so that kind of challenge of being aware of the physical difficulties that somebody with neurological problems has got. (Pete)

Alternatives to floor-based practices were consequently proposed and these involved finding comfortable sitting practices:

> So, if we're sitting on chairs, it's still good to have cushions or zafus [meditation cushions] to get your legs in position so your legs aren't too far down, you know. A good 90-degree angle is a good sitting posture that you can adopt. I do spend quite a long time talking to people about sitting postures and how they can get themselves comfortable. (Tricia)

Posture should therefore be prioritised, with supine meditation potentially substituted for sitting practice, and adequate resourcing needed to achieve comfort.

*Theme 8: Inclusion of pacing*

When working specifically within the context of delivering mindfulness teaching for people with chronic health conditions, all participants recommended that pacing, as often used for pain management programmes, should be incorporated: "because of my condition [SCI] I've had to bring pacing in as part of mindfulness, which is quite unusual, it's not part of any other mindfulness programme" (Sarah). Pacing is not common in standardised MBSR/MBCT programmes. Yet, pacing was conceptualised as part of mindful self-management, spreading beyond the boundaries of the teaching session, into broader daily life: "I've only got so many marbles in a day of energy, so I've got to be very careful what I do. Pacing, yeah, and that's part of mindfulness training. Get used to pacing, yeah" (Pete). Jade expanded this further with reference to how she teaches pacing:

> Exploring how you pace your day and how you can work with [your condition], mindfully to avoid boom and bust, and how you can become more aware of how you can take back the driving seat really. Keeping diaries, pacing diaries and how you would analyse the diaries and set baselines and build upon that. (Jade).

Though pacing is regularly employed in other clinical intervention programmes, the specific element that was considered for working with pacing with the current study population was working with resistance to pacing:

> I suppose the different mindful element is noticing the resistance [to pacing]; you know the 'I don't want to do this right now', and again because you noticed that and you're aware of it, you have a choice. Well do I resist it and not pace, or do I think well I don't really want to do it but yeah, I am going to. I'm going to follow the prompt, I'm going to have a rest, I'm going to have a stretch. (Sarah)

By assimilating pacing into an adapted mindfulness programme, and prioritising mindful awareness of resistance, pacing was felt to offer specific advantage that warranted its use by people with SCI/MS/FND.

*Theme 9: Teaching from experience*

The final theme advocated by practitioners with SCI/MS/FND was the importance of teaching from a position of expertise. They felt that teaching as a peer and as someone living with a health condition was highly beneficial: "I think, from what I've felt, is there's been like a bit of authenticity there in some ways. People almost like look harder. I'm not saying people listen to me more, but I can say 'I've tried this'. 'I've tried this and it worked for me'" (Pete). This experiential teaching stance extends to modelling the adapted practices they recommend:

> The way I'm anticipating the sessions that there are in the teaching of the course, is that I will have to model what I am telling people to do, in order to be able to teach it. So, it will involve me moving and changing positions and doing different things throughout that teaching process. (Jenny)

All participants additionally noted that their ability to teach comes from their personal practice, such that they can teach what they have experienced:

> I think it's important to have my own space and a sit before I do the course. Because you need to be grounded and I think it's *really important* to be embodied when you're teaching. And you can only be embodied if *you* do it. You can't teach something if you don't fully know – if you're not fully aware of it. So, I'll do that (Tricia).

This theme therefore represents the value in mindfulness teachers implicitly providing peer modelling and authenticity when teaching from their own practice as someone living with SCI/MS/FND.

*Round 2 Results: Cognitive Interviews and DELPHI analysis*

The results of the cognitive interviews (Round 2) with the expert panelists provided detailed feedback on the presented table of recommendations for practice, In Round 2, response rate from the panel was 100% (n = 5). Eight out of ten of the recommended practice items reached consensus and were approved by the panel. Mean±standard deviation scores for the revised items in the recommended practice table presented in Round 2 were 4.7±0.35 for importance and 4.44±0.35 for clarity. The mean clarity and importance ratings for each recommendation statement are presented in Table 3. Participants raised comments regarding the variability in the individual's experience of NI and therefore suggested that recommendations were widened to explicitly allow course participants to personalise their practices to ensure

inclusivity: “Communicate the importance of adjusting and applying the principle to yourself, the importance of being flexible to personalise the practice” (Male panellist with SCI). In association with this, the use of the word ‘normalise’ was suggested for inclusion. Specific to the recommendation regarding mindful movement, panellists noted that some, but not all clients with NI may use wheelchairs, therefore wheelchair use should be included but mindful movement should remain broadened, for example, “mindful movement includes wheeling, walking and transferring” (Male panellist with SCI).

Round 3 Results:

Round 3 focused on re-review, re-rating and the optimum wording of the recommendations. Full response rate was maintained (10%, n = 5). Consensus was reached overall, with all recommendation domains endorsed, representing 10 domains of adaptation to mindfulness-based practices, and 26 statements. A further two statements under the domains of ‘body scanning’ and ‘optimum timelines’ were not endorsed. The first regarded the optimum number of weeks for a mindfulness-based intervention adapted for NI. This was felt to over specify requirements, such that they could not be applied to particular formats mindfulness teaching “You might have a foundation course, and could then have follow-up, so ‘introduction to mindfulness’, then a second course as a continuation course (higher level)” (male panellist with SCI). The second statement focused on the use of ‘energetic engagement’ as a tool for developing awareness of areas of the body were sensation was not present. It was felt that different presentations of NI would change the appropriateness of such techniques: “some people can, some people can’t, what about phantom limb” (female panellist with SCI). All panellists recommended these items for removal to strengthen the final

recommendations. The full recommendations for adapted practice which reached consensus from the expert panel are presented in Table 4.

## Discussion

The themes developed from the qualitative interviews demonstrated key recommendations for the adaptation of mindfulness-based practices for populations with neurological disability, presented as SMALL PROMPTS (**S**kin/bladder/bowel management, **M**indful movement, **A**ccessible training, **L**anguage **L**eadership, **P**ermissive p**R**actice, **O**ptimising timelines, **M**anagement of Posture, Inclusion of **P**acing, **T**eaching from experience and body **S**canning). The SMALL PROMPTS recommendations (presented in Table 4) demonstrate how teaching practices could be adapted in delivery to promote tailored MBIs for people with NI.

Firstly, teachers need to encourage heightened awareness of skin, bladder and bowel management during MBIs, monitoring session timing and breaks, whilst also ensuring that appropriate and accessible facilities are available. Encouraging postural adaptation and responsiveness to skin, bladder, and bowel management needs within-session and when planning, is in accordance with skin, bladder and bowel recommendations for clinical best practice and rehabilitation (Wheeler et al., 2018). The SMALL PROMPTS approach recommends that mindful walking should be reconceptualised as mindful movement, such that movement meditation instructions are inclusive for wheelchair users and visualisation techniques may be used where sensation is not present. In this study, the reworking of the term of mindful walking to become mindful movement, potentially involving wheeling, responds directly to the barriers identified by three qualitative research studies investigating

mindfulness for SCI/MS, in which patients highlighted the importance of this term for inclusivity (Finlay et al., 2021; Hearn et al., 2020; Simpson et al., 2019). Consequently, careful selection of venues for face-to-face courses must be made, ensuring that there is adequate space and accessibility for wheelchair users, with online courses provided where possible and inclusive technology used to ensure that people without hand function or transport/proximity to the course can access the intervention.

The language choices used by the mindfulness practitioner were felt to be extremely important.The need for language to remain person-centred and sensitive throughout teaching was emphasised, such that teaching language projects acknowledgement and appreciation of sensory presence and sensory absence, equally. This inclusive perspective is also modelled in the need for teaching practices which offer a flexible and permissive approach to mindfulness practices, such that participants could tailor their use of different postures (sitting, standing, lying and moving) to their physical capabilities. Additionally, openness in discussing and encouraging ways in which postural comfort could be explored through provision of physical staff support (including carers) and appropriate practical aids (cushions, props), was considered paramount. To embed such changes and incorporate physical health guidelines (Wheeler et al., 2018), the SMALL PROMPTS approach suggests reducing the programme length: weekly two-hour sessions were recommended, with 90 minutes of scheduled teaching time and 30-minute breaks to facilitate social connection and physical (skin/bladder/bowel) health management, alongside shortened meditation practices. The rationale for these adaptations is increasingly demonstrated in research into brief mindfulness interventions, with a recent systematic review demonstrating that 79 of 85

studies utilising brief mindfulness showed positive, clinically meaningful improvements across one or more health outcome measure (Howarth et al., 2019).

The technique of pacing, often used in cognitive-behavioural approaches and pain management, should be integrated into MBIs with this population and prospective resistance to pacing should be explored within the sessions. Given the physical restrictions and the presence of difficult pain, fatigue and other neurological symptoms experienced by people with SCI and MS, the inclusion of pacing is a strategic recommendation. The evidence for the benefits of pacing demonstrates a protective impact, improving physical activity adherence levels in chronic illness populations, essential for reducing cardiovascular mortality (Abonie et al., 2020). More broadly, teaching from experience was recommended, as peer modelling and authenticity is gained by teachers teaching from their personal knowledge of living with NI and maintaining an active mindfulness practice. By including formally trained mindfulness teachers with experience of neurological disability, outcomes may be enhanced: peer teaching and mentoring for people with SCI has been found to be transformational (Shaw et al., 2018) and peer health coaches increased self-management behaviours in mentees (Skeels et al., 2017). It is possible, therefore, that inclusion of mindfulness teaching by peers may optimise the outcomes of MBIs.

Collectively, the SMALL PROMPTS approach prioritises adaptation, flexibility and tailoring. Indeed, the importance of tailoring and flexibility in the delivery of mindfulness-based practices with NI populations, has been demonstrated in stroke survivors (Wang et al., 2019). Modifying mindfulness to account for post-stroke communication difficulties was found to have high levels of patient-perceived feasibility and perceptibility, which linked to greater

willingness to engage in at-home practice of the mindfulness-based approaches. Similarly, in cancer patients, tailoring intervention delivery to patient preferences improved mental health and quality of life (Carlson et al., 2014). The importance of communicating the validity and acceptability of adapted practice within MBIs is, therefore, key if people with NI are to be encouraged to become autonomous in their self-directed use of mindfulness, thereby enhancing outcomes (Parsons et al., 2017).

*Limitations and future recommendations*

It is recognised that the current study is limited by its small sample of formally trained mindfulness teachers with significant teaching experience and neurological disability. Prolonged efforts were made, for more than a year, to recruit as widely as possible within the inclusion and exclusion criteria and the sample represents, to the authors' best knowledge, all possible candidates from the database of accredited mindfulness teachers held by Breathworks. The recommendations advocated in this paper were reviewed by an expert-patient panel in accordance with DELPHI guidelines (Coulter et al., 2016), and the SMALL PROMPTS approach responds directly to further qualitative research with patients with NI (Hearn et al., 2020). The SMALL PROMPTS recommendations therefore assimilate both patient and professional viewpoints. The current study provides strong recommendations for the development of future MBIs in populations with NI. Further research could prioritise intervention development based on the content of the SMALL PROMPTS adapted guidelines, to review their viability for inclusion in intervention delivery.

*Conclusion*

The SMALL PROMPTS recommendations from the current research delineate the

considerations that clinicians and mindfulness practitioners need to account for when formulating MBIs for NI. They guide formulation and present a strong opportunity to develop targeted and adapted MBIs suitable for populations with NI. The benefits of engaging with mindfulness-based practices should be equally available to people with and without sensory loss. The current study has, therefore, offered a structure which extends the knowledge of how best to approach teaching mindfulness in populations with sensory loss. This means that inclusive MBIs can be adapted to be clinically accessible and appropriate to people with NI.

*Ethical Standards*

This research was approved by the University of [blinded for peer review] ethics committee and was conducted in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

*Conflict of Interest*

The authors declare that they have no conflict of interest.

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Fig 1.

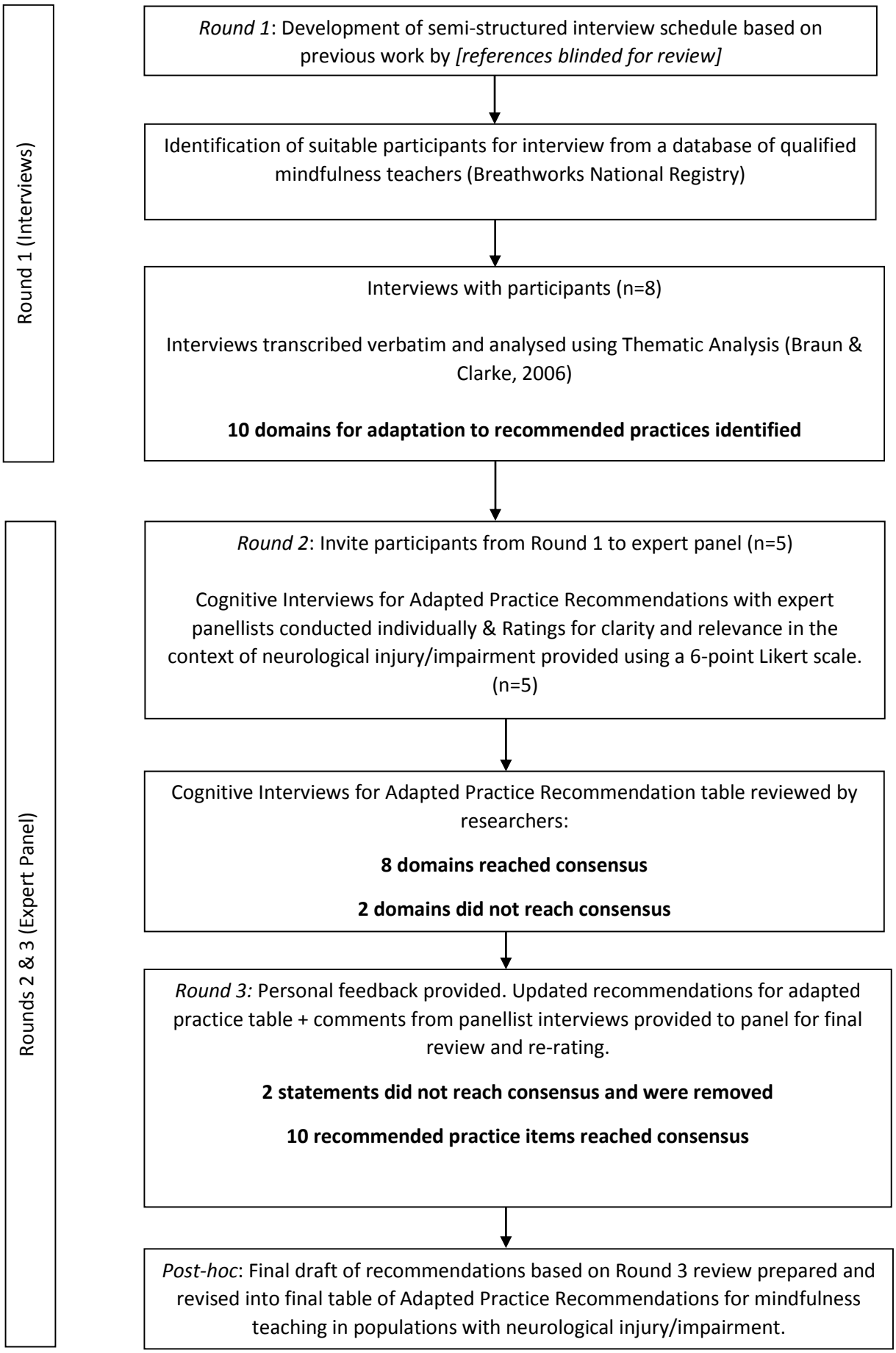

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Table 1. Participant Demographic Characteristics

| Pseudonym | Age | Gender | Diagnosis | Date of Diagnosis | Employment Status | Teaching experience (years) | Daily practice (hours) |
|---|---|---|---|---|---|---|---|
| Jade | 35 | F | FND | 2012 | Part-Time | 5 | 1 |
| Sarah* | 58 | F | SCI (I) | 1976 | Full-Time | 20+ | 11 |
| Pete | 42 | M | MS | 2010 | Part-Time | 6 | 7 |
| Keith* | 59 | M | SCI (C) | 1983 | Unemployed | 20+ | 3 |
| Robert* | 55 | M | SCI (C) | 1984 | Part-Time | 10 | 1 |
| Tricia* | 46 | F | SCI (I) | 1995 | Full-Time | 12 | 3 |
| Elise* | 59 | F | SCI (I) | 2009 | Retired | 20+ | 10 |
| Jenny | 60 | F | SCI (C) | 1979 | Volunteer | 7 | 1 |

Notes. FND = Functional Neurological Disorder; MS = Multiple Sclerosis; SCI (C) = Complete Spinal Cord Injury; SCI (I) = Incomplete SCI; *Denotes expert panel membership.

Table 2: Interview Schedule

| **Eliciting Questions** |
| --- |
| 1. Can you tell me a little about how and why you first came across mindfulness?<br>a. How has your 'journey' as a mindfulness teacher developed since then?<br>b. Could you tell me about a typical day/schedule for you, personally, when you are teaching mindfulness? |
| 2. What made you want to teach mindfulness?<br>a. Please tell me about some of the challenges you have faced in becoming a mindfulness teacher and how you overcame these. |
| 3. Can you tell me about your experience of teaching mindfulness when you have an SCI/MS?<br>a. What training have you done?<br>b. How do you adapt your teaching to account for SCI/MS/FND? |
| 4. If you were designing a mindfulness programme specifically for people with SCI/MS/FND, what might you include?<br>a. Why might you include those things?<br>a. What might you avoid or adapt?<br>b. How might you structure and run the course? |

Table 3: SMALL PROMPTS Recommendations Development and Scoring

| No. | SMALL PROMPTS: Acronym | Domain of Adaptation | Round 2: Recommendation Statement | Round 2 Scoring M(SD) | | Round 3: Final Recommendation Statement | Round 3 Scoring M(SD) | |
|---|---|---|---|---|---|---|---|---|
| | | | | Importance | Clarity | | Importance | Clarity |
| | | | | *Mean (SD)* | *Mean (SD)* | | *Mean (SD)* | *Mean (SD)* |
| 1 | **S** | **S**kin, bladder and bowel management | Maintain quality checks on postural aids to reduce likelihood of pressure sores | 4.6(0.89) | 4.4(0.89) | Maintain quality checks on postural aids and adjust, if necessary, during the meditation, to reduce likelihood of pressure sores | 5(0) | 5(0) |
| | | | Explicitly discuss and allow for bladder and bowel management within-session | 4.6(0.89) | 4.6(0.55) | Explicitly discuss, facilitate, and expect bladder and bowel management within-session | 5(0) | 5(0) |
| | | | Schedule elongated coffee breaks (minimum 30-minutes) for bladder and bowel management | 5(0) | 4.4(1.34) | Schedule elongated coffee breaks (minimum 30-minutes) for bladder and bowel management | 5(0) | 5(0) |
| 2 | **M** | **M**indful Movement | Mindful movement and wheeling can be substituted for walking | 5(0) | 4.4(0.89) | Mindful movement, including wheeling, can be substituted for mindful walking | 5(0) | 5(0) |
| | | | Account for neurological impairment when formulating mindful movement | 5(0) | 4.8(0.45) | Account for neurological injury/impairment and/or sensory absence when formulating mindful movement | 5(0) | 5(0) |
| 3 | **A** | **A**ccessible training | Utilise larger venues | 5(0) | 3.6(1.67) | Utilise spacious venues | 5(0) | 4.4(0.89) |
| | | | Ensure venues have wheelchair accessibility throughout (including toilets and facilities) | 5(0) | 4.8(0.45) | Ensure venues have wheelchair accessibility throughout (including toilets and facilities) | 5(0) | 5(0) |
| | | | Facilitate online delivery | 5(0) | 3.6(1.67) | Facilitate options for online delivery | 5(0) | 5(0) |
| | | | Ensure that interventions are accessible to those without hand function. To facilitate this, incorporate inclusive technology where possible | 5(0) | 4(1) | Ensure that sessions are accessible to those without hand function or with limited movement. To facilitate this, incorporate inclusive technology where possible | 5(0) | 5(0) |
| 4 | **LL** | **L**anguage **L**eadership | Prioritise inclusive language | 5(0) | 4.4(0.89) | Prioritise inclusive language relevant to a range of sensory experiences | 5(0) | 5(0) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | Adapt sensation-based language to encompass awareness of loss of sensation | 4.4(1.34) | 4(1.41) | Adapt sensation-based language to encompass awareness of loss of sensation | 5(0) | 5(0) |
| | | | Use terminology 'Mindful Movement' not mindful walking | 5(0) | 5(0) | Use the terminology 'Mindful Movement' not mindful walking | 5(0) | 5(0) |
| 5 | **PR** | **P**ermissive p**R**actice | Communicate openness to adjustment and flexibility in use of practices | 4.8(0.45) | 3.6(0.89) | Communicate an invitation to adjust position as necessary and discuss the importance of flexible, personalised practice(s) | 5(0) | 5(0) |
| 6 | **O** | **O**ptimum timelines | 4 x weekly sessions | 4.6(0.89) | 4(1.73) | *REMOVED* | | |
| | | | Teaching session length of 90-minutes (maximum) | 5(0) | 4(1.41) | Teaching session length of 90 minutes (maximum) | 5(0) | 5(0) |
| | | | Coffee breaks of 30minutes (minimum) | 5(0) | 4(1.41) | Coffee breaks of 30 minutes (minimum) | 5(0) | 5(0) |
| | | | Prioritise brief practices (3-5 minutes) | 4(1.41) | 4.2(1.10) | Employ shorter practices (5-10 minutes) | 5(0) | 4(1.41) |
| 7 | **M** | **M**anagement of Posture | Teach the four mindfulness stances (sitting, standing, lying, movement) | 5(0) | 3.4(1.34) | Teach about the four mindfulness stances (sitting, standing, lying, movement) and encourage exploration of optimal position(s) suitable to the individual | 5(0) | 5(0) |
| | | | Prioritise sitting practices | 4.2(1.30) | 3.6(0.89) | Normalise sitting practices | 5(0) | 5(0) |
| | | | Maintain awareness of wheelchair-related discomfort and support wheelchair-based postural adaptation | 4.2(1.10) | 4(1.22) | Maintain awareness of wheelchair-related discomfort and support and encourage wheelchair-based postural adaptation where applicable | 5(0) | 5(0) |
| | | | Explicitly discuss comfort and review optimum meditation postures | 5(0) | 4.8(0.45) | Explicitly acknowledge the importance of comfort and making postural/stance adjustments to maintain comfort during meditation | 5(0) | 5(0) |
| 8 | **P** | Inclusion of **P**acing | Introduce pacing and energy management | 4.8(0.45) | 4.8(0.45) | Introduce pacing and energy management | 5(0) | 5(0) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | Utilise activity diaries and timing | 4.4(0.89) | 4.2(1.30) | Utilise activity journals and self-monitoring of activities to prevent boom and bust cycling | 5(0) | 5(0) |
| | | | Include discussion and exploration of resistance to pacing | 4.4(1.34) | 4.4(0.89) | Include discussion and exploration of resistance to pacing | 5(0) | 5(0) |
| 9 | **T** | **T**eaching from experience | Review opportunities for trained peer-led mindfulness teaching | 4.8(0.45) | 4(1.41) | Where possible, involve peer mindfulness teachers in teaching from their lived experience | 5(0) | 5(0) |
| 10 | **S** | Body **S**canning | Use visualisation to explore both sensory presence and sensory absence equally | 5(0) | 3.8(1.10) | Explore both sensory presence and sensory absence equally | 5(0) | 5(0) |
| | | | Prioritise the importance of maintaining full body awareness despite sensory loss | 4.6(0.55) | 3.6(1.52) | Encourage awareness of the whole body despite sensory impairment/loss | 5(0) | 5(0) |
| | | | Explore use of 'energetic engagement' with the body as a whole | 3.8(1.10) | 2.8(1.48) | *REMOVED* | | |

Table 4. Adaptations to Mindfulness-based Interventions for Neurological Injury/Impairment: The SMALL PROMPTS guidelines

| SMALL PROMPTS | Domain of Adaptation | Recommendation Statement |
|---|---|---|
| **S** | **S**kin, bladder and bowel management | Maintain quality checks on postural aids and adjust, if necessary, during the meditation, to reduce likelihood of pressure sores<br>Explicitly discuss, facilitate, and expect bladder and bowel management within-session<br>Schedule elongated coffee breaks (minimum 30-minutes) for bladder and bowel management |
| **M** | **M**indful Movement | Mindful movement, including wheeling, can be substituted for mindful walking<br>Account for neurological injury/impairment and/or sensory absence when formulating mindful movement |
| **A** | **A**ccessible training | Utilise spacious venues<br>Ensure venues have wheelchair accessibility throughout (including toilets and facilities)<br>Facilitate options for online delivery<br>Ensure that sessions are accessible to those without hand function or with limited movement. To facilitate this, incorporate inclusive technology where possible |
| **LL** | **L**anguage **L**eadership | Prioritise inclusive language relevant to a range of sensory experiences<br>Adapt sensation-based language to encompass awareness of loss of sensation<br>Use the terminology 'Mindful Movement' not mindful walking |
| **PR** | **P**ermissive p**R**actice | Communicate an invitation to adjust position as necessary and discuss the importance of flexible, personalised practice(s) |
| **O** | **O**ptimum timelines | Teaching session length of 90 minutes (maximum)<br>Coffee breaks of 30 minutes (minimum)<br>Employ shorter practices (5-10 minutes) |
| **M** | **M**anagement of **P**osture | Teach about the four mindfulness stances (sitting, standing, lying, movement) and encourage exploration of optimal position(s) suitable to the individual<br>Normalise sitting practices<br>Maintain awareness of wheelchair-related discomfort and support and encourage wheelchair-based postural adaptation where applicable<br>Explicitly acknowledge the importance of comfort and making postural/stance adjustments to maintain comfort during meditation |
| **P** | Inclusion of **P**acing | Introduce pacing and energy management<br>Utilise activity journals and self-monitoring of activities to prevent boom and bust cycling<br>Include discussion and exploration of resistance to pacing |
| **T** | **T**eaching from experience | Where possible, involve peer mindfulness teachers in teaching from their lived experience |
| **S** | Body **S**canning | Explore both sensory presence and sensory absence equally<br>Encourage awareness of the whole body despite sensory impairment/loss |