

Experiences of mindfulness-based cognitive therapy for premanifest Huntington's disease

**Running title:** MBCT for premanifest HD

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## **Abstract**

**Background:** Psychological difficulties such as anxiety, depression and irritability are common in Huntington's disease, even for premanifest individuals. However, very little evidence exists of psychological approaches to manage this distress. We have conducted a feasibility study with an embedded qualitative component to investigate the possibility of using mindfulness-based cognitive therapy (MBCT) and present here the findings from the qualitative data.

**Objective:** To investigate the experience of premanifest individuals learning and practising mindfulness through completing a course of MBCT.

**Methods:** Twelve premanifest individuals completed a course of MBCT and attended three follow up reunion meetings over the following year. Eleven participants agreed to be interviewed post-course and ten participants one year post-course about their experience of the course and any impact on their lives. Seven participants nominated a friend or relative (supporter) to be involved in the research, of whom six agreed to be interviewed post-course and two at one year about the impact of the course on the participants. Data were analysed using reflexive thematic analysis.

**Results:** Four themes were constructed from the data: 1) A meeting of minds: the group facilitating learning and support; 2) Mindfulness is hard, but enables more effective emotional management; 3) Mindfulness can change the relationship with self and others; and 4) Benefiting from mindfulness: the importance of persistence.

**Conclusions:** The participants who completed the course found it beneficial. Some participants reported reductions in psychological distress, a greater sense of calm and better emotion regulation, with some of these positive changes also noticed by supporters. MBCT is worthy of further investigation for this population.

**Keywords:** Huntington's disease, mindfulness, depression, anxiety, irritability, emotion regulation, premanifest, presymptomatic

## **Introduction**

Individuals with the Huntington's disease (HD) gene expansion, including those at the premanifest stage, can experience low mood, anxiety, and irritability as well as other psychological difficulties [1-5] and these can have a greater impact on health related quality of life than motor problems [6]. Current understandings of psychological distress in HD often privilege a biomedical perspective. However, such understandings minimize a number of psychological factors that may be important for individuals with HD. For example, lifetime levels of psychological distress experienced by those carrying the expanded HD gene and those who do not (but have a parent with HD) are similar [7] indicating that growing up in a family with HD may be a factor [8]. It is also important to recognise the impact of receiving a positive test result for the gene expansion, knowing one will develop a life-limiting condition, possibly with first-hand experience of the effects of the disease from a parent. A review of the quantitative work on the impact of genetic testing found that distress was not consistently associated with test result (i.e. whether carrying the expanded gene or not) and that distress fluctuated over the years following the test result [9]. However qualitative findings suggest a more nuanced picture on learning of expanded gene carrier status with a complex array of emotions experienced [10-13]. In addition, beliefs about the illness and ability to cope are important contributors to psychological distress [14] including in HD [15, 16]. Therefore, psychological interventions which are able to adjust unhelpful appraisals, coping strategies and cognitive patterns could potentially reduce the psychological distress experienced by individuals living with HD.

While pharmacological treatments may sometimes be effective to alleviate distress, evidence is limited [17] and they may not be the preferred treatment option for all. A lack of published research exists on the acceptability or efficacy of psychological interventions for people with HD, despite these individuals being open to psychological intervention [18]. Considering those

who are pre-manifest or at an early disease stage, only two previous studies have focused specifically on psychological interventions (rather than multidisciplinary treatments). One, a case study, found cognitive behavioural therapy (CBT) reduced anxiety and depression for a pre-manifest individual [19]. The other used a patient education programme (PEP-HD) with a group of individuals who were pre-manifest or early manifest which involved psychoeducation and aspects of CBT [20]. This showed significant improvements for both premanifest and symptomatic participants in one measure of depression (but not another), improvements in specific components of coping, and improvements in anxiety for symptomatic individuals only.

We focus here on a related approach, mindfulness-based cognitive therapy (MBCT) [21]. This has a growing evidence base for alleviating distress [22, 23] and, along with similar mindfulness programmes, may also improve some aspects of cognitive functioning [24, 25]. MBCT has been shown to alleviate distress in other neurodegenerative conditions, e.g., Parkinson's disease (PD), multiple sclerosis (MS), and motor neurone disease [26-29]. It has also shown the potential to improve some aspects of cognition in PD [30], but to date has not been investigated in HD. Mindfulness-based interventions can cultivate acceptance of long term conditions [31], and the social interaction and support gained by being part of an MBCT group with others with a similar condition can also be beneficial and enhance the benefits of mindfulness training [29], which may be particularly important for those with a rare condition like HD. MBCT, unlike standard CBT, was specifically designed to offer the cost-efficiency and other benefits of a group-based treatment. Furthermore, it was considered that MBCT's emphasis on skill acquisition would enable individuals to develop a skillset to cope with the immediate low mood but also future challenges.

MBCT is typically taught by a mindfulness teacher to a group over 8 weeks. MBCT provides "integration of core cognitive therapy principles with sustained mindfulness practice" p.5 [21]. In each two-hour class participants learn and take part in specific activities to which

they bring intentional present-moment attention. These include the body scan, mindfulness of breath, and mindful movement with opportunities to share their experiences with each other and the class teacher. These practices, in and outside class, also help participants become aware of patterns of un-planned and un-intended mental activity. Realising that these can be unhelpful at times and are often below the threshold of full awareness they also learn to detect unhelpful thoughts and feelings, thus acquiring the important ability to choose to return attention to present reality. Each week participants are expected to do up to an hour of home mindfulness practice daily and again experiences of this, including any difficulties, are explored in the following class [21].

Through these exercises, individuals learn to focus their attention in a particular way and to be present in the moment, bringing a non-judgemental stance to their experiences [32]. Course participants learn to recognise unhelpful thought processes and disengage from them by focusing on present moment experiences. This meta-cognitive process of disengagement from the content of thoughts, or “stepping back” is often referred to as de-centring [21, 33, 34]. Through these processes they become aware that thoughts and feelings are temporary mental events rather than facts, and learn to relate to their self and experiences more kindly [33]. Often the 8-week course is followed by reunion meetings which help participants to maintain their mindfulness practice [21].

Knowledge of HD status affects not only the person with the disease, but also their social and family network [35]. As the disease develops, the emotional difficulties experienced by individuals with HD, along with physical symptoms, appear to have the greatest effect on family members’ levels of stress associated with taking a caregiving role [36, 37]. It follows that any support offered to people with HD resulting in improved psychological wellbeing would impact positively on those around them [38]. Furthermore, family and close friends are ideally placed to comment on any changes experienced by an individual with HD and how

these affect their daily lives. This is particularly the case as families can note subtle changes in the emotions and behaviour of premanifest individuals prior to them meeting the criteria for diagnosis [4], which rely heavily on the presence of more obvious motor symptoms [39-41]. Therefore, seeking the views of family members and friends (hereafter called supporters) on the effects of an intervention is also important.

This paper presents findings of qualitative study which was embedded in a feasibility study which investigated the feasibility of conducting a future randomised controlled trial of MBCT with individuals with the expanded HD gene who were premanifest or at an early disease stage, with the aim of reducing distress [42]. We were only able to recruit premanifest individuals to the feasibility study and therefore only their experiences are presented in this paper. Quantitative data were collected from participants and their supporters at multiple time points up to one year after the intervention. The feasibility outcomes (including quantitative findings) are reported elsewhere [42]. This paper presents the findings of the qualitative data gathered from premanifest individuals and their supporters immediately post the MBCT course and one year after the intervention. The qualitative data were collected to address the following questions: What was the experience of attending an MBCT course? How has mindfulness been experienced in the lives of individuals with HD and their supporters since participating?

## **Materials and Methods**

### ***Participants***

Participants with the HD gene expansion (hereafter participants) were recruited from two HD centres in the north of England. Inclusion criteria were confirmed HD gene expansion at the pre-symptomatic stage or symptomatic at stage 1 (i.e. score 11 or 12 or 13 on the Total Functional Capacity Scale [43] which is part of the Unified Huntington's Disease Rating Scale [44]); experiencing low mood at last appointment (based on clinical judgement); aged 18 years or over; able to understand and speak English; and availability to commit to taking part in the

course on a regular basis. Exclusion criteria were changes in medication in the previous 6 weeks and active suicidal intent. Supporters had to be aged 18 or over and be the partner, family member or close friend of the participant.

The original intention was to recruit to two courses: one for pre-symptomatic individuals and one for those at an early disease stage. However, no symptomatic individuals were recruited. We decided therefore to let pre-symptomatic individuals attend the second course. Both courses of MBCT therefore included only those who were pre-symptomatic. However, as we were still struggling to recruit sufficient participants for the second course, three participants from the first course repeated the course to form part of the second cohort (repeating a course is not unusual in MBCT in clinical practice with other conditions). For the first cohort, 11 participants started the course and 10 participants completed it. For the second cohort, six participants started the course (including three repeaters) and four completed it (one new participant and one repeater left). Thus, overall 14 participants started the course as new participants and 12 completed it (one left due to non-related health reasons and travel difficulties and one left saying it was not for them). Interview data were available from 11 participants at immediate follow up (one was not contactable) and 10 participants at one year (one participant, who had attended the reunions, declined to be interviewed). Seven participants had a supporter involved, of whom six agreed to be interviewed at immediate follow up and two also agreed to be interviewed at one year.

Demographic details of the 11 participants and six supporters are given in Table 1; ranges are given to preserve anonymity. All participants were at the premanifest stage. Participants' ages ranged from 24 to 64 years and supporters' ages from 26 to 72 years. All participants and all supporters reported their ethnicity as white British or white Irish. Time since receiving the

genetic test result ranged from 1 to 21 years and seven participants were taking antidepressant medication.

All 11 participants attended at least five sessions of MBCT (which was deemed necessary for completion) and of the 11, all but one attended at least one reunion meeting. Attendance of at least half the classes is usually considered necessary for completion e.g.[45, 46].

Table 1 about here

### ***Recruitment***

Ethical approval was gained from the UK National Research Ethics Service Committee North West - Lancaster (15/NW/0238). The study was registered on [clinicaltrials.gov](https://clinicaltrials.gov), identifier NCT02464293.

Potential participants were invited to participate by a member of their clinical team when attending routine clinic appointments. Where patients had already consented to be contacted about research, they were also contacted by telephone, email or letter. Potential participants could then contact the research team themselves to hear more about the research or give their consent for the clinical team to pass their details on to the research team. The research team then contacted the potential participant. The potential participant discussed the study with a member of the research team and also with the mindfulness teacher to find out what participation involved. During this time, the possibility of having a supporter involved in the research was also raised with the participant. If they were interested, then a pack of information for the supporter was sent to the participant to give to the supporter. Similarly, the supporter then contacted the research team to indicate their interest in taking part. A member of the research team then met the participant and supporter at their house or another convenient

location, either together or separately, to take consent (and administer the initial measures for the feasibility study).

### ***Intervention***

Both MBCT courses ran for 8 weeks, facilitated by the same qualified mindfulness teacher following the manualised MBCT protocol [21]. No specific adaptations were made regarding the HD population, but participants were advised not to participate in practices which were painful or physically difficult. Supporters did not take part in the intervention.

Following the MBCT course, participants were invited to attend three reunion meetings facilitated by the same teacher which took place three, six and nine months after the course had ended. These consisted of 2-hour sessions revisiting the principles and practice of mindfulness and exploring any difficulties participants were having regarding mindful practice.

### ***Data collection***

After completing the intervention, participants and supporters were contacted to arrange separate semi-structured interviews at the person's home or at a community venue. These were audio recorded. The topic guides (see Tables 2a-d) for the interviews was based on similar previous research which has explored experiences of MBCT [29, 47]. Participants were asked about motivations and expectations prior to the course; their experiences of the course and of learning mindfulness; any changes that they had noticed in their lives; and their views on continuing practice. Supporters were asked about expectations; how the participant had found the course and the impact on family/friends of the demands of the course; any changes they had noticed in the participant and in their family/social interactions; and whether they thought the participant would keep up mindfulness practice. Interviews lasted 30-80 minutes with participants and 30-50 minutes with supporters. Participants and supporters were approached

again after one year for a second interview when some interviews also took place over the phone. These interviews asked about current views of the course and whether any changes had been maintained. Interviews at one year lasted 14-51 minutes with participants and 24-31 minutes with supporters. Following data collection the interviews were transcribed verbatim. For the repeating participants, only data relating to their first course was included (at which point they did not know about a possible second course) so as to be comparable with the other participants.

Tables 2a-d about here

### *Analysis*

Reflexive thematic analysis using an inductive approach was used to analyse the data [48, 49]. Initially three datasets were analysed separately (supporters, participants immediate post-course and participants at one year follow up). For each group transcripts were read in detail, and utterances considered possibly relevant to the research questions were coded. Codes which reflected similar meanings were gathered together and examined for relevance to the research question. Those not relevant were discarded. Central organising concepts for the groups of codes were identified, which enabled the construction of subthemes and then higher order themes [48, 50]. However, as the concepts identified across the three datasets were similar, the three analyses were combined. The transcripts were constantly re-examined throughout the process to ensure that the themes still related to the original texts.

### **Results**

Four themes were constructed from the data: 1) A meeting of minds: the group facilitating learning and support; 2) Mindfulness is hard, but enables more effective emotional

management; 3) Mindfulness can change the relationship with self and others; and 4) Benefiting from mindfulness: the importance of persistence. Quotations from data collected immediately post-course are indicated by PC and those at one year by 1Y. [...] indicates abbreviated text.

***Theme 1– A meeting of minds: the group facilitating learning and support***

Before start of the course, participants had mixed feelings about meeting others with the HD gene. Several participants had not met any other affected individuals outside their own family, which could leave them feeling isolated:

“I’d never met someone with the HD gene. I felt like the only one” (Participant 1, 1Y).

Another participant expressed the difficulty she faced in not having anyone to talk to about HD:

“My family didn’t want to talk about it, and I couldn’t talk about it to my friends.” (Participant 11, 1Y).

Therefore, the possibility of meeting and connecting with others with the gene was seen positively, as a way of connecting with others. However, at the same time there was trepidation that the group would be attended by others who were at a later stage of HD and thus participants would see their future selves:

“You think... are they going to be [...] people that are really on a different level to you?, like more poorly or such and you think, bloody hell, is that your type of future ahead of you?” (Participant 4, PC)

This concern was expressed by supporters too. Indeed, some participants had deliberately avoided meeting others or had had distressing experiences when attending support groups and finding others at more advance stages or finding groups were only attended by relatives discussing how hard it was caring for someone at more advance stages. Thus, the prospect of meeting other people with the gene expansion was understandably daunting. Finding out that the MBCT group was only for people who were pre-manifest helped ameliorate the concerns.

While some participants said they would have been comfortable in a group with individuals with other conditions, most interviewees remarked it was good to work with those in a similar situation. Indeed, the shared identity and sense of community also was a motivator for some participants to attend and become active members of the group:

“Seeing people with HD who weren’t family members and not showing signs of the illness. That definitely made me feel better. Seeing people there that have the same problems as me. That got me to go there and be a part of the group.” (Participant 4, 1Y)

However, the group setting itself was felt by one participant to be hard to be comfortable in:

“It’s the first time I’ve ever done anything like this and it felt strange,” (Participant 7, 1Y)

In addition to the MBCT course itself, the reunion meetings which took place over the year were also seen as a time to reconnect with the community and find encouragement and support:

“I think when you are perhaps... a bit flawed or new to things that can be a bit scary, that to have the support of other people in a similar situation is very powerful.” (Participant 1, 1Y)

***Theme 2: Mindfulness is hard, but enables more effective emotional management***

There appeared to be a general consensus among participants that practising skills related to mindfulness required commitment and dedication from the individual; it was an active process that required work and effort to sustain. As one participant commented:

“I didn’t realise meditation was going to be so hard. I thought it would be easier to get inside your own head.” (Participant 7, PC)

However, with practice, participants found mindfulness could anchor them in the present rather than allowing fear to drive them into the future. There were considerable benefits of developing a moment-to-moment awareness:

“Before [the course] I’d walk the dogs and I’d be in my HD head just worrying about HD. Just depressive, negative thoughts. Just feeling like I wanted to die. [...] But now I know that I have to kind of stop, start looking at things and just see what’s happening right now this minute.” (Participant 8, PC).

Similarly, another participant stated:

“I needed my thoughts to be shepherded back into the day, because they were in the future. And it causes anxiety and it doesn’t alter the future ... I saw it as an opportunity to try and learn about not to worry too much, right now in this moment, you know, I’m okay.” (Participant 1, PC)

Specific practices were also helpful for managing particularly stressful events, including those specifically associated with HD, such as being with family who were symptomatic:

“I just found that doing anything at all, even if it is just focusing on the breath even just for a minute or two just it does have a really profound effect on your sort of stress levels.” (Participant 10, PC)

Participants also noticed that they were able to step back from what was happening and notice their thoughts and behaviour. As a result, one participant had become less irritable and less impulsive:

“I just take a step back a little bit and [...] and just think about what the situation is before maybe jumping in a little bit.” (Participant 4, PC)

This ability to step back and take time to respond was also noticed by supporters:

“She [participant] doesn’t fire out...she thinks before she will say something...more than she used to.” (Supporter 3, PC)

De-identifying from thoughts, or de-centring, also helped participants recognise when their thoughts were unhelpful, which meant they could sometimes prevent their mood worsening:

“You know there’s little like signs isn’t there and you’re headed off, you think right I’m going down here now, I’m going to stop now, ‘cos I know where it leads and I don’t want it to lead it to there, I don’t want it to get to that stage. Whereas before I didn’t know so I’d just go hurtling down.” (Participant 11, PC).

For another participant negative experiences were still a part of his life, however his reaction to them, viewing them as transient, lessened the impact and duration of these experiences:

“I won’t pretend I’ve not had dark moments... but I deal with them a lot better. Occasionally I can’t and I have to just experience it. But... the mindfulness still comes in... it’ll pass... feelings, emotions: they arise, they’re there for a while and then they pass...and I just have that mantra. Before I would have been so critical of myself, telling myself I’m weak. But not anymore.” (Participant 2, 1Y).

This lessening of self-critical thoughts alongside an increase of self-compassion and self-kindness was noticed by several participants. For example, one participant described how self-compassion, along with de-centring, led to a more accepting relationship towards her thoughts and a reduction in rumination:

“Thoughts come and... I don’t feel guilty. I just think... “Why are you thinking about that today?”...it’s not the same as before. It would have led to deeper thoughts, more damaging thoughts.” (Participant 8, 1Y).

For this participant, recognising her emotions also allowed her to manage the demands that were placed on her:

“Well, I’ve learnt to read my emotions better, because I wasn’t before as much. And I think because of that I’ve learnt to... I suppose I’m learning how much I can cope with and then draw the line. Because that’s being kind to myself and it’s helping me cope.” (Participant 8, PC)

### ***Theme 3: Mindfulness can change the relationship with self and others***

Perhaps due to their view of emotional difficulties having a physical basis, at the start participants tended to have low expectations as to whether the course would help, but nevertheless approached it with an open mind:

“I didn’t expect it to help me as much as it has but I hoped that it [would].” (Participant 6, PC)

However, following completion, everyone reflected on the positive impact of learning mindfulness, although inevitably changes were greater for some than others.

Several participants commented that taking the course had made them feel calmer and less stressed. Being less stressed had different impacts on different participants, but changes noticed included being less anxious, performing fewer checking behaviours, being less irritable when driving and low moods being less persistent. Being able to respond more flexibly to their thoughts and emotions also helped participants feel less overwhelmed and more able to cope. For example, at one year, one of them stated:

“I feel like I got control of my... brain/head again because I’ve got management techniques.” (Participant 4, 1Y)

Supporters also noticed the change in participants, and that this had positive benefits for those around them:

“I think...he’s calmer, it obviously impacts on me if he’s calmer about things” (Supporter 4, PC).

Another supporter described the participant developing the ability to be comfortable with silence and stillness and that this had a positive effect on their relationship:

“Our relationship generally feels...a little bit calmer. We seem to be able to almost sit together more often.” (Supporter 5, PC)

Some supporters also suggested that communication between themselves and participants had improved. The increased awareness of emotions mentioned by participants may have played a role in this process:

“He’s probably a little more likely to actually be a bit more open and speak about things whereas in the past he’d just shut down.” (Supporter 4, PC).

Another benefit was that some supporters also suggested that their partner/friend was more receptive and willing to listen to them:

“During the occurrence of the course...I just felt like he was giving me a bit more time, I’d come home from work...and he’d let me offload for a little while.” (Supporter 5, PC).

Stepping back in situations (cf. theme 2) also gave participants more choice over reactions to interpersonal situations which could have a positive influence on family dynamics:

They [participant and another family member] can rub each other the wrong way....She was...using what she’d learnt to not react...actually taking one step back mentally and going ‘right OK, well we don’t have to have this argument do we?’....So I think that it had an effect that way (Supporter 8, PC)

Being on the mindfulness course also appeared to “open some dialogue” and provided a platform for discussing emotional wellbeing between supporters and participants – “a way of talking about how he [participant] is” (Supporter 2, PC). Thus being on the course appeared to serve as an indirect, and perhaps less confronting, way for participants and supporters to engage in meaningful and open discussions about their wellbeing.

Another benefit voiced by some participants and supporters was avoiding medication for emotional difficulties and MBCT was seen as a more proactive strategy:

“It’s just better than just taking pills forever, isn’t it? It’s something you can actually practise, physically do, as well as doing it with other people. Get feedback and support.” (Participant 6, PC)

For other participants who were already taking medication, MBCT was seen as complementary therapy:

“It was coming to a point with even with [medication] that I was still getting wound up. [...] it’s [mindfulness] definitely helped to the next level now, to sort of combat the aggression side of it or feeling irritated or annoyed.” (Participant 4, PC).

For some participants, there was not much change in their wellbeing or their everyday lives, but they appreciated having the skills for use in the future:

“I don’t feel radically different but there is something actually in at least I’ve got some confidence that I’ve got some tools that I can use.” (Participant 9, PC)

Another similarly viewed mindfulness skills as a “resource when I need it” (Participant 5, 1Y).

For other participants, they recognised that mindfulness had begun to permeate all aspects of their lives:

“It isn’t about just sitting in a room and meditating, it’s [...] everything. Not just sitting there for half an hour, thinking about my body then it all being different. It’s all encompassing, over everything that you do.” (Participant , PC)

Indeed for a small number of participants, the changes seemed deeper than specific behaviours or cognitions. Practising mindfulness had changed their relationships to their selves and way of interacting with the world. For one participant, standing back from her thoughts had helped her “see myself more clearly” (Participant 1, 1Y). Another reported that friends had commented to him “it [mindfulness] just makes you more content with yourself and nicer to yourself” and the participant agreed “it’s had a massive effect on me” (Participant 2, 1Y). Both these participants described the mindfulness course as “life changing”.

#### ***Theme 4: Benefiting from mindfulness: the importance of persistence***

The course and subsequent reunions appeared to create a protected space for mindfulness and motivated individuals to attend and to engage in regular practice:

“Having a couple of hours sectioned off for the course on a Saturday made it much easier. And because you’ve got someone taking you through it, saying this is your homework, you need to do this... you can fit it in.” (Participant 7, 1Y).

Reunions were felt to have extended the benefits of commitment to the course, being viewed as a chance to refresh skills and revisit the principles of mindfulness as well as acting as a motivator to keep practising:

“It’s so easy to sort of go off track a bit so it was really good to...have a refresher and sort of recommit to keeping it up.” (Participant 10, 1Y)

When considering specific mindfulness practices learnt during the course (e.g. the body scan, sitting meditation or mindful movement), participants had individual preferences, but they all generally completed at least some of the home practice each week. However, at the one year follow up performing the longer formal practices had decreased or ceased for most individuals. Three participants who were committed to developing their formal practice were looking to join other mindfulness groups. Indeed, they noticed mindfulness practices continued to make a difference in their lives:

“I would actually have more anxiety in the course of the day where I hadn’t done the mindfulness. So I had my own evidence to support the fact that doing the mindfulness in the morning helped me.” (Participant 1, 1Y)

However, for most participants longer formal practices were recognised as potentially being useful, but were not practised regularly as it was too difficult to fit it into their busy lives:

“I’m not going to do the full 45 minute sit. I do need to do more of that though to be very honest [...] but I’m just too busy.” (Participant 9, 1Y)

Nonetheless, at one year most participants noticed that they were still continuing with informal practices:

“I don’t meditate or anything like that and I don’t do the body scan, I try and do [mindfulness] when I’m walking, around the park and things. [...] I’ll be sort of meditating in my head and focusing on positives.” (Participant 4, 1Y)

Mindfulness was also continuing to be used in stressful situations, in particular noticing the breath and anchoring oneself in the present moment:

“If I feel angry about anything I take a deep breath and... just stand and think. I do use that way of thinking in the moment and accepting the moment as well.” (Participant 3, 1Y)

One supporter indicated that being aware of mindfulness herself enabled her to prompt the participant during difficult situations:

“I’ll remind him occasionally and sort of say ‘why don’t you use your techniques...that you’ve been taught before?’ And you know...he does...and he will use them.” (Supporter 4, PC).

Others had their own prompts:

“I’ve got the little printout on mindfulness on the door of my fridge so I do [...] I think ‘oh right I must remember to do that.’” (Participant 3, 1Y)

Although supporters were generally appreciative of their partner/friend having been offered the MBCT course, they were also conscious of the need for further support:

“I think one of my questions is the support after [...] what continues afterwards?”  
(Supporter 8, PC).

The end of the MBCT course and reunions was seen as a loss and supporters expressed concern that there would be little else available in terms of psychological interventions in the immediate future.

## **Discussion**

This study presents the experiences of individuals with premanifest HD participating in group MBCT and to explore any impact of learning mindfulness on their day-to-day lives and that of their supporters. Participants generally saw many positives in attending a course with others with the same condition. However, as noted in PD [29] and MS [51], prior to the course both supporters and participants were concerned about meeting others who were in the later stages of the disease. Indeed, those who had attended support groups where those with more advanced disease were present had found it distressing. Both participants and supporters were relieved on discovering that the MBCT course was only for premanifest individuals and this could be important to consider when designing and advertising future courses.

Having a course specifically for those with the HD gene expansion was important for most participants. Knowing that they were “all in the same boat” appeared to be important in fostering a sense of commonality among participants, again similarly expressed by course participants with MS [51]. This also appears consistent with research adopting group MBCT and mindfulness-based stress reduction (MBSR) with individuals with a variety of health conditions. In particular, the the group format has shown to be a supportive therapeutic environment which provides motivation to persevere with mindfulness practice [47] as well as reducing isolation and stigma [52], these latter issues also being salient for premanifest individuals with HD [53-55]. However, it should also be acknowledged that groups are not

comfortable for all [52]. Attending the reunions over the following year also gave participants the opportunity to sustain relationships over time which may have further contributed to the positive findings.

The findings also indicate how specific skills developed in the course were implemented by participants to manage HD-related distress. De-identifying from thoughts, or de-centring, often seen as a key aspect of MBCT [21, 33, 34], enabled participants to relate differently to their experiences. Rather than becoming engaged with (and potentially immersed in) the content of thoughts and associated emotional responses, they shifted towards awareness of thinking as an ongoing process which could be observed. This in turn enabled participants to reflect on, and where appropriate change, their habitual responses. Consequently, as previously observed following MBCT [56], ruminative and worrying thoughts which previously had increased anxiety and low mood were reduced. This is consistent with evidence showing how focusing on the present moment could reduce distress and even allow enjoyment of the present [33, 52].

In addition, de-centring alongside increasing awareness of emotional states gave some participants greater flexibility in responding to everyday situations, which in turn resulted in greater emotion regulation, i.e. the “processes by which individuals influence which emotions they have, when they have them, and how they experience and express these emotions” [57, p.275]. Emotion regulation has been widely recognised as playing a pivotal role in the successful implementation of both coping skills [58, 59] and psychological adjustment to chronic disease [60]. However, the current literature around emotion regulation in the HD population is very limited [61]. In particular, the only two studies focusing on symptomatic individuals showed contrasting results [62, 63], while the only study to date involving premanifest individuals reported no generalised difficulties of emotion regulation, but a potential predictive role of subclinical depressive symptoms over deficits of specific emotion

regulation components [64]. Nonetheless, considering a potential early onset of the well-established emotion recognition deficits found in HD's symptomatic stage [65], as well the reports from families of premanifest individuals suggesting problems congruent with emotional regulation difficulties [4], it is encouraging that mindfulness could be beneficial in this regard.

In addition, mindfulness practices, such as focusing on the breath, even for a short time, reduced stress in specific situations. Participants gave examples of using this strategy both in day-to-day life and in HD specific situations, such as being with relatives with more advanced HD, which is known to be particularly stressful for gene carriers [66]. Encouraging greater self-kindness and reduced self-judgement is also an intention of MBCT and increased self-compassion, as reported by participants, may be another mechanism which leads to reduced distress [67]. Self-compassion has been conceptualised in various ways, but tends to include being sensitive to one's own pain and suffering, while meeting that suffering with kindness, empathy [68, 69], sympathy, non-judgement [69], courage, equanimity and patience [68]. Self-compassion was perhaps more prevalent in the follow-up than the post-course interviews, suggesting that it took time to develop; a finding in common with MS participants [51]. In general, many participants experienced a greater sense of control over their emotions and behaviour, and greater perceived control is often linked to greater wellbeing [70].

All the participants who completed the course reported that they found the course worthwhile. For some participants, mainly those reporting few difficulties pre-course, the benefits were predominantly that they felt they had skills for the future, rather than any noticeable immediate change in wellbeing. However, for others the changes were more marked, with a reduction in stress and increased sense of calm being reported by several participants and their supporters. Given that irritability and symptoms of anxiety can be present in HD, including for those who are premanifest [7, 8, 71, 72], this is an important

possible benefit from MBCT. Some participants and supporters were also pleased that mindfulness gave them an alternative or additional approach to managing difficulties instead of, or alongside, medication. As has been noticed previously in other conditions [52], as well as by two participants here, mindfulness can be transformational, with individuals developing a new outlook on life and a new relationship with the self.

Some supporters also noticed changes in relationships and family or social interactions. It is known that knowledge of the genetic test result impacts on families in a variety of ways, changing the family system [35]. In particular, reduced affective involvement (family members' interest in each other) and reduced family functioning have been reported by both premanifest individuals and their families, along with families reporting reduced communication [73]. Following MBCT, some supporters reported increases in communication and connection with the participants as well as reduced reactivity in stressful family or social situations which improved family and social functioning. Previous research has suggested that relating more mindfully to self leads to more mindful relations with others, including an increased awareness of triggers in interpersonal exchanges, improved perspective-taking, empathy and communication [74].

Attendance at the course was good. Only two participants who started the classes dropped out and most who completed the course (attended at least five sessions) attended at least one reunion meeting. However, most participants reported difficulty in keeping up formal practice once the course had ended. This is not unusual following MBCT, and it is recommended that participants have access to ongoing classes to maintain their practice (and thus maintain the benefit; [21]). This could be particularly important for individuals with the HD gene who can experience difficulties with apathy and motivation [8, 75]. It has been noted that supports such as booster sessions are important for maintaining mindfulness practice in people with MS [31]. However, despite not maintaining formal practice, many participants were still maintaining

informal practices at one year and the reunions were noted as helpful in this regard. The continued use of informal practices has been identified as an important factor in maintaining long-term beneficial effects in an acceptance-based mindfulness intervention [76].

Our classes were just for those with the HD gene but classes can be run with supporters present too [e.g., 77], or separate classes can be run for them. One supporter who was aware of mindfulness was able to prompt the participant to use the skills learnt, and this support could be enhanced if supporters also learnt such skills. Also, some supporters noted that they would find the skills useful for managing their own stress.

Considering limitations of the present study, it is recognised that it focused solely on two MBCT groups with one teacher. Additionally, all participants engaged with their status of having the HD gene and actively sought support with this through attendance at medical appointments as well as engaging in research. MBCT is an approach which requires commitment and persistence so will not be suitable for all. Furthermore, two participants left the course after only one session and their data are not included here. One left due to non-related health reasons and transport difficulties, but the other left due to dislike of the approach and their opinions are not represented in the data. Also, it is unclear to what extent benefits were obtained from particular aspects of the course and in particular the importance of the social support obtained. Should future randomised controlled trials be conducted, it may be worthwhile to consider a control group containing some elements of social support, to enable further understanding of the benefit of mindfulness practices specifically. Trying to capture further the experiences of those who chose to leave courses would also be beneficial.

While all who completed it were generally positive about the intervention, supporters in particular expressed their concern about psychological support once the research came to an end, which again highlights the lack of psychological interventions and psychological support

available for this population [4, 78]. One limitation of MBCT is that it is traditionally (although not universally e.g., [79]) delivered in a group format which can be restrictive in needing everyone present at the same time, and not everyone is comfortable in groups. Therefore, individual interventions are also needed so that people with the HD gene have a similar choice in psychological therapy that is available to individuals with other chronic and/or neurodegenerative conditions. This study only presents the data for pre-manifest individuals and therefore any possible effects of mindfulness practice on symptomatic individuals remains unknown.

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### **Conflicts of interest**

The authors have no conflict of interest to report.

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**Table 1:** Participant and supporter demographics

<b>Participant number</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Time since genetic test (years)</b>	<b>Supporter number</b>	<b>Age (years)</b>	<b>Gender</b>
1	≥50	Female	>10	-		
2	≥50	Male	>10	2	≥50	Female
3	≥50	Female	>10	3	≥50	Male
4	<50	Male	6-10	4	<50	Female
5	<50	Male	1-5	5	<50	Female
6	<50	Female	1-5	6	<50	Male
7	<50	Female	6-10	-		
8	<50	Female	1-5	8	≥50	Male
9	≥50	Male	6-10	-		
10	<50	Female	1-5	-		
11	≥50	Female	1-5	-		

**Table 2a:** Topic guide for interviews with participants immediately post-course

**Expectations and motivations**

Explore motivation for taking part in the research, psychological wellbeing at the time of entry, prior experiences of psychological interventions or mindfulness and expectations of the course.

*Example questions:*

Can you remember back to when you were first approached – what were your first thoughts about the course?

What led to your decision to take part? How were you feeling in yourself when you decided to take part?

Did you have any expectations as to what the course would be like?

Have you experienced anything similar in the past (psychological therapy and/or mindfulness)?

Did you expect the course to help you?

Did you have any worries before starting the course?

**Experiences during the course**

Explore participants' experiences of taking the course including their experiences of practising mindfulness (during the classes and at home) and their experiences of being on the course with others.

*Example questions:*

How did you find the mindfulness course? Did you find that the course was as you expected beforehand?

How was the initial class? And further classes?

What did you like/dislike about the classes?

How did you find learning/doing the practice of mindfulness?

Did the experience of this change throughout the course? How?

How did you find the teaching parts of the course, for example learning more about depression?

What was it like being in a class with others?

Did you notice any changes in yourself during or following the course?

If we were to run the course again, what do you think we should do differently?

**Experiences after the course**

Explore ongoing practice of mindfulness and their appraisal of the impact of having participated in the course.

*Example questions:*

What are your thoughts about the course now?

Did the course help you at all? Was this more or less than you expected?

Do you still practise mindfulness? If yes, how often, which practices do you do?

Do you think you will keep practising?

How are you feeling in yourself now? Do you think this has changed as a result of being on the course?

Has being on the course changed how you feel about Huntington's disease/how you cope?

What are your thoughts regarding the reunion meetings?

Is there anything else you would like to tell us or think we should know?

**Table 2b:** Topic guide for interviews with participants one year following the course

**Ongoing practice and understanding of mindfulness**

Explore whether they have an ongoing practice of mindfulness and their appraisal of the impact of having participated in the course.

*Example questions:*

What are your thoughts about the course now?

Do you still practise mindfulness? If yes, how often, which practices do you do? Do you think you will keep practising?

If not, what do you think contributed to this? Would you consider another course?

How are you feeling in yourself now? Do you think this has changed as a result of being on the course? Do you think the ongoing practice helps you? How?

Has being on the course (and ongoing practice if relevant) changed how you feel about HD/how you cope?

**Reunion meetings (if participant has attended)**

Explore experiences of reunions

*Example questions:*

What are your thoughts regarding the reunion meetings?

How have they influenced your mindfulness practice?

How have you found meeting up with other course participants?

Is there anything else you would like to tell us or think we should know?

**Table 2c:** Topic guide for interviews with supporters immediately post-course

**Expectations and motivations**

Explore the wellbeing of the supporter and participant pre-course and the supporter's expectations of the course.

*Example questions:*

Can you remember back to when you and your relative/friend were first approached – what were your first thoughts about the course?

What led to your decision to take part in the research? How were you feeling in yourself when you decided to take part? How was your relative or friend feeling?

Did you or your relative or friend have any expectations as to what the course would be like?

Have you or your relative or friend experienced anything similar in the past?

Did you expect the course to help your relative or friend?

Did you have any worries before your relative or friend started the course?

**Experiences during the course**

Explore how supporter found the experience of their friend or relative taking the course including their experiences of the friend or relative practising mindfulness at home.

*Example questions:*

How did your relative or friend find the mindfulness course? Was as you both expected beforehand?

What did he/she like/dislike about the classes?

How did they find learning/doing the practice of mindfulness in class and at home?

Did the experience of this change throughout the course? How?

[Where relevant] What impact did this have on life at home?

Did you notice any changes in your relative or friend while they were doing the course?

How did they find the teaching parts of the course, for example learning more about depression?

How did they find being in a class with others?

If we were to run the course again, what do you think we should do differently?

**Experiences after the course**

Explore whether their relative or friend has ongoing practice of mindfulness and any impact on participant and supporter

*Example questions:*

What are your thoughts about the course now?

Did the course help your relative or friend at all? Was this more or less than you expected?

Do they still practise mindfulness?

Do you think they will keep practising?

How are they feeling now? Do you think this has changed as a result of being on the course? How are you feeling now? Do you think this has changed as a result of your relative or friend being on the course?

[If participant with HD has changed] Have there been any effects on your relationship or on family life?

Has your friend or relative being on the course changed how you feel about HD/how you cope?

Is there anything else you would like to tell us or think we should know?

**Table 2d:** Topic guide interviews with supporters one year post-course

**Ongoing practice and understanding of mindfulness**

Explore relative or friend's ongoing practice of mindfulness and supporter's appraisal of the impact of having participated in the course.

*Example questions:*

What are your thoughts about the course your relative took part in now?

Does he/she still practise mindfulness? If yes, how often? Do you think he/she will keep practising?

If not, what do you think contributed to this? Would he/she consider another course?

How is your relative or friend feeling now? Do you think this has changed as a result of being on the course? Do you think the ongoing practice helps? How?

How are you feeling now? Do you think this has changed as a result of your relative or friend being on the course? Has your home life been affected? Has your relationship with your relative or friend been affected?

Has being on the course (and ongoing practice if relevant) changed how you or your relative or friend feel about HD/how you cope?

**Reunion meetings (if participant with HD has attended)**

Explore supporter's view of reunion meetings

*Example questions:*

What are your thoughts regarding the reunion meetings?

Do you think they influenced your relative or friend's mindfulness practice?

How have they found meeting up with other course participants?

Is there anything else you would like to tell us or think we should know?