

Mindfulness for Parkinson's Project – Report

Azizë Stirling

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This document reports the activities and findings of the Mindfulness for Parkinson's Project during the 9 months between July 2022, and March 2023. Its aim is to inform and to encourage a conversation with and amongst the 'stakeholders' - so not just the people with Parkinson's who participated, but also their families, associated charities, and the wider Parkinson's community. This includes the researchers, doctors, nurses, therapists and teachers who have been engaging with them professionally, as well as our funders, the National Lottery Community Fund.

There are two parts to this report. **Section one** is an update to the report written in May 2021 (<https://oxfordparkinsons.org.uk/documents/mindfulness/20210901-report.pdf>) **Section two** contains the responses of the participants taken from their Individual Learning Plans at the end of the two most recent 8-week course

Section One

In our last National Lottery funding application we wrote that: “we will continue with **the programme** that is working well, expand the programme **to more successfully include carers**, and begin to develop measures to **make the programme more sustainable long term**.”

So, first, **the Programme**.

The period between the end of the funding in April 2021 and the beginning of the next funding in July 2022, the programme was pared back. There was a weekly online drop-in of mindful movement and meditation which was done on a pro-bono basis, whereas the face2face mini-retreats were done on a donation basis. We ran an 8-week course, also by donation, which was ostensibly for carers, but in the end, what had started out as 8 participants – 5 of them carers – ended up with 5 participants – only 2 of them carers.

July, we had our funding back, which allowed us to step up our three-session introductions for newcomers, increase our drop-ins from once/week to twice, and run two, eight-week foundation courses. We also started a ‘deepening’ course for people who had completed the 8-week course. This included meeting for an hour once a week along with meeting face-to-face for 3 four-hour sessions. We were also able to include an advanced 8-week course, Mindfulness Based Compassionate Living.

We also tried two sessions – one on breathing, the science and the practice: the other on anxiety, where we investigated how the practice of mindfulness might have relevance in these areas for PwPs. The one on anxiety was particularly well received.

To more successfully include carers

There have been about eight ‘carers’ involved with the Programme over the past three years, with four of those people now widowed. It is interesting to note that of the 3 carers who dropped out of the course spoken of above, two of them cited pressure of finding the time.

A good case can be made to include ‘carers’ in a mindfulness programme that can offer help and support. Parkinson’s affects more than the person diagnosed with it – it can also profoundly impact the lives of those near and dear, and often in ways that can be difficult to deal with openly. The University of Lancaster study shows that the ‘carers’ of PwP’s suffered more during lockdown than their partners. We have found that it is not only us that find carers/family members complicated/difficult to reach and support. We remain in conversation with local Parkinson’s groups and health professionals on how to address this more effectively.

Make the programme more sustainable long term

As mentioned above we have been working on a programme that can deepen participants mindfulness practice/understanding to the point where they might have the skill and confidence to become ‘lay-mindfulness-teachers in this community. Also, enabling PwPs to become ‘lay’ mindfulness teachers takes developing a sense of agency to another level. This is an ongoing project that shows promise. Also, we could see that there was interest amongst the physios and Parkinson’s nurses to become more mindfulness savvy so that they can more knowingly refer their clients. Over this past period we have had 2 sessions: one with a few of the physios; and another with the Parkinson’s Nurses. We hoped that this might include looking at the possibility of integrating mindfulness into their own classes/practices. Progress here has been slow, due in part to the pressures on time the clinicians within the NHS are currently experiencing.

An effective mindfulness programme for people with people with Parkinson’s can become more sustainable if PwPs are in a better position to be less dependent on outside funding, and the availability of mindfulness teachers who are sufficiently familiar Parkinson’s. There is also a role for the teachers, physios, nurses, and doctors, who, by being well-informed and experienced, can support and encourage PwPs in their mindfulness.

More about the 8-week course.

We seem to have settled on using the Breathworks 8-week course - ‘Mindfulness for Health’, which comes in a book which won the BMA Popular Medicine Award first prize for 2014. Previously, we had used 2 other well-known courses which were aimed more at the general public, whereas this course targets people with chronic illness much more directly.

In our last report we noted that, judging by the comments of the participants, there were 3 features of the course that stood out:

*it's emphasis on how to work with acceptance in the context of compassion (accepting what we can, as much as we can, moment to moment, while being held in kindness) and that with developing compassion for ourselves can come more compassion for others, and the way the two can build on each other.

*The second was the 'pacing diary' as a practical means of bringing kindness, self-care, and insight into the way we live our lives from day to day.

*The course material was given added depth with the inclusion of relevant studies and scientific findings.

This year, the comments from the participants show that along with what is listed above, there are more features coming into play/focus that are making a difference. This is one of them:

*Primary and secondary symptoms/suffering. Learning to recognise and the difference between these two, and then understand the implications is fundamental to this course. To quote one of the participants: *"I have found it very useful to be able to see the difference between primary symptoms and secondary symptoms – ie my response (reaction) to the primary. This helps focus my attention on what's happening as it happens. You can't change the primary, but you can make a choice about the secondary. This makes me feel that I can choose, develop coping skills and not feel locked in. Being able to choose to stop, and breath whenever I become aware that I need it. Over the time of this course, I find that I am becoming more sensitive to what's going on in my mind and body and have more confidence that I can respond appropriately with my mindfulness skills. This opens the door to compassion for me, and that also changes how compassionately I can respond to others. It has changed the extent to which I can appreciate life around me and be grateful. This goes on to have positive consequences and creates virtuous circles. The more I can bring myself into the present moment the less time I spend in suffering-producing negative states"*.

Individual Learning Plans

One of the principal achievements of the group was to develop a way of documenting the course, which could also serve as a means for the participants to monitor and consolidate their own learning. Our solution was to draw up an Individual Learning Plan. Before the start of the course each person was given the opportunity to fill out the Individual Learning Plan, which consisted of lists of issues people with Parkinson's might face. The first list could be called 'primary' or 'root' issues/symptoms. The next list, secondary issues, or ones that could be said to result from the mind/body's response to the primary ones. The final list could be seen as the desired and conscious responses to the primary and secondary. We asked people to choose up to 4 issues from each of the lists that they found had most impact or relevance to them. The individual learning plans are reviewed with each participant at the end of each course. This produces a wealth of qualitative material (also see previous report), which can be shared with the group, the advisory board, and the wider community.

The responses to these questions and others are to be found in Section 2 of this report.

Section two

Participants' responses

The Primary Issues/Symptoms

At the end of the course, we asked the participants, if over the time of the Breathworks course have they noticed a change in how they were experiencing the Primary and Secondary 'symptoms'; or, if there had been a change in perspective.

*Below find participants responses. (please note that each symptom/issue chosen is underlined, and each quote is separated from the next with *****)*

With anxiety there has been a change in how I experience it. Not as intense and possibly not as frequent. The biggest change has been that now I know better how to deal with it, ie work with my breath I and refer to the tool box list of 'smile, breath. Check tension in neck and shoulders.'

Swollen painful joints - Accepting the pain more and also noticing the subtle changes in the pain which helps me see that I'm not stuck in it. Fatigue/lethargy- The steadiness of daily practice lifts my mood which means that I don't feel so tired. This allows me to be more focused and motivated. The grief has been more manageable, I'm getting a different perspective, I have more positive thoughts and memories, it's no longer so overwhelming. Anxiety: daily mindfulness has helped me accept situations as they are results in less anxiety. low mood; see above. rumination: I know that the more I stay in the moment, the less I ruminate. When go walking with my dogs I engage more with what is around me esp nature and take great pleasure in it. lack of motivation; being part of the group helped motivate me to keep up my practice. And seeing how 'feeling on my own' adds to lack of motivation, 'feeling connected' ads to it. Generally, more enthusiastic about life. This has added to my self-confidence - that this is something I can do that works.

isolation - am making more effort to be with other people but trying to get the balance right and not over-do it. Feeling calmer - it's quite subtle but there is difference.

Stiffness - Softens after a meditation. Pain. Did a bodyscan to see if I could get to the root of a splitting headache, and to my surprise discovered that it was my eyes. I breathed through them and it all but went away. slowness (mental or physical) before the course I would become very impatient when my movement slowed down - sometimes even panicky, but now I seem to have developed more of an attitude of compassionate acceptance. This allows me to be more patient. When I recognise some of the secondary suffering like anxiety, I use some of the meditations we've been doing on the course to work with it. low mood: can be triggered by fear, which is sometimes difficult to pin down, but

perhaps related to fear of not knowing what's going to happen. The meditation practice brings me back to the reality of present moment and stops me catastrophising.

Although the symptoms are still there, I'm learning to work with them rather than against them. I'm beginning to realise that when I have negative thoughts, they aren't me. I'm not those negative thoughts. And when I become aware of these thoughts I stop, pause, and breath, and with that breath I feel things change – which is quite significant and very helpful. I do have to remember to do it, but this is becoming easier and more familiar. And better at stopping myself from overdoing it which makes my symptoms worse. I can calm the anxiety by stopping and breathing. depression / low mood; stopping, and questioning my own negative thinking, and turning it around – meditation can be very useful for this. It can help with 'allowing'. I have to watch my lack of motivation. It can mean that I avoid doing things I know are good for me, and just as important, something I will enjoy. So noticing more often my counter-productive resistance. independence/dependence; I'm losing my independence but can accept this a bit more. But there is a fine line between allowing this and being able to see they are doing too much.

I have found it very useful to be able to see the difference between primary symptoms and secondary symptoms – ie my response (reaction) to the primary. This helps focus my attention on what's happening as it happens. You can't change the primary, but you can make a choice about the secondary. This makes me feel that I can choose, develop coping skills and not feel locked in. Being able to choose to stop, and breath whenever I become aware that I need it. Over the time of this course, I find that I am becoming more sensitive to what's going on in my mind and body, and have more confidence that I can respond appropriately with my mindfulness skills. This opens the door to compassion for me, and that also changes how compassionately I can respond to others. It has changed the extent to which I can appreciate life around me and be grateful. This goes on to have positive consequences and creates virtuous circles. The more I can bring myself into the present moment the less time I spend in suffering-producing negative states. Sleep: sleep has improved because I'm no longer getting into a state about it. Starting off the day feeling rested makes a huge difference to mood and physical symptoms. And this also means that I am able to feel joy and appreciation. Balance/mobility - more generally my other symptoms may not have improved, and fact some have become worse but I relate differently to them and don't experience them in the same way. Loss of dexterity (eg hand writing). With dexterity I have found exercises that bring improvement. Independence/dependence axis: I used to resent people helping me now am now I just feel grateful.

Change in attitude; for example, more in touch with feelings of gratitude, more accepting generally of what I have no control over in my life. Feel that my mood has lifted. I find that if I meditate every day my mood stays more in balance, it's as important as my medication, in fact I would say that it is more effective than my medication. The longer that I have been involved in mindfulness, and the deeper I go, and the more I understand, the better/more effective and richer it has become. I am more focused and better motivated in most areas of my life. Swollen painful joints – using meditation to get through /ease bouts of

painfulness. Fatigue/lethargy – accepting more when it happens but also find that often I feel more energised than before. Loss of suppleness which can affect ease of movement. More awareness around my body so I'm able to look after myself more sensitively. Grief - again can use meditation to bring back perspective and also change body chemistry for the better.

I have made a connection between stress and how I experience my symptoms. If the stress is lowered my symptoms improve and vice versa.(esp cognitive and language issues) Cognitive difficulties (memory,confusion) there has been fear around not being able to remember, and with it, loss of confidence. Language processing (nominal/anominal aphasia) see above , and I've gained confidence. I can see now that I have also been experiencing social anxiety, and now it's improved as well. So part of my change of strategy is to take more time and plan more thoughtfully when I can see how to avoid unnecessary stress. Pain - by doing meditation when I'm experiencing pain, it takes my mind off the pain and then the pain seems to disappear. Pacing has improved my fatigue. Anxiety - this is better largely due to improved planning. Panic - currently I am not experiencing panic. Lack of motivation improved with increase in confidence. Frustration - not being able to get as much done in a day as I want. Much less driven than I was but this tendency runs deep.

There has been a change in how I deal with the symptoms, now, especially since the anxiety has become much more of a primary symptom. Being able to stop when I am feeling the anxiety build and then try a whole range of coping strategies: meditations, yoga, connecting with someone, going out for a walk, reading – just listening to what I need now. Beginning to recognise the thoughts which are symptomatic and if let run, feed the anxiety. Also finding that cultivating gratitude or writing the daily appreciation list very useful. The time I've spent on this course has given me growing confidence in my ability to use and understand better the skills and perspectives I've learned. However, right now it can be hard to see some of this in perspective, given the intensity of the anxiety that I am now experiencing.

Desired/conscious responses

The question we asked was: ' Looking over the 'desired responses' you've chosen, could you say how, over the time of this course, you've learned more about these responses and how to put them into practice? No need to limit yourself to the ones you've chosen.

I still find it difficult to accept my situation but meeting the others in the group, sharing and laughing has helped with the acceptance. The course has allowed me to focus on compassion and I find that I'm better able to relate to people I find difficult. Learning to be not so tough on myself which also seems to be related to acceptance. Not letting Parkinson's dominate my life: It might have softened a bit. I find myself more likely to do things (like a tap-dancing class in person) that I might have previously not considered. - that I can see myself, and can be seen by others, as someone who can contribute to the wellbeing of my friends, family, my community – and myself. Am adjusting to what I can sensibly do

now and choose more carefully what I commit myself to do. I find with more careful consideration and planning I can ease the stress and fatigue of activities that I've previously just bashed my way through. Being more in the present Checking more often that I'm not get caught up in the past or worry about the future etc and making sure that I can come back to the present. The three min breathing space is very good for this. It brings me back to my surroundings and things that I can find pleasant and positive – sunshine, fresh air, nature other people, friendships and more.

Relaxed and calm- the course gave me the opportunity to re-visit the meditation and breathing as an aid to relaxing and becoming calmer.

I feel that the course has encouraged a conscious cultivation of gratitude and appreciation, and find that the more I do it, the more I do it. facing my fears; more work to do. - relaxed and calm I could say, moreover, that this has increased.

Developing coping strategies; The 3 minute breathing space I use when I need it throughout the day esp if I'm feeling anxious. Also knowing that I have a choice and not stuck in a situation is very effective to help me cope. Acceptance; this has been a game changer. Practicing acceptance has made a noticeable difference to how I experience my primary symptoms. Been helpful knowing that I have a choice to how to respond to life's events. Being happier, more content Feeling I have more control, choice, a mindfulness practice that works, and the confidence in my ability to look after my life, and living more in the present all contributes to greater happiness. I feel that the course has encouraged a conscious cultivation of gratitude and appreciation, and find that the more I do it, the more I do it. facing my fears; more work to do. - relaxed and calm I could say, moreover, that this has increased.

Acceptance; more accepting of my situation, which is a good component of my change in general. facing my fears; being able to accept more has meant that my situation is less terrifying. Not letting Parkinson's dominate my life; More pro-active. Accepting to do things that I would have previously avoided. I feel braver. That I can see myself, and can be seen by others, as someone who can contribute to the wellbeing of my friends, family, my community – and myself links in with not letting Parkinson's dominate my life. And also, feeling more open and confident.

Cultivating gratitude and appreciation; Things like acts of kindness whether giving them or receiving them has more meaning now. And appreciation of the small things can be so rewarding. At the beginning I thought that I was relying on determination to get the most out of the course by doing all of the home practice and reading, and that kept me motivated and

committed. But later it felt more like confidence /trust or even faith in the course that made it easy to carry on. relaxed and calm- feeling at home in my body. During the course I seemed to develop the ability to become more aware of my secondary symptoms and change how I was, to feeling more relaxed and calm. not letting Parkinson's dominate my life; I developed a wider lens to take in more of the pleasant/pleasurable aspects of daily living despite the disease.

Developing coping strategies ;As mentioned previously, beginning to recognise when I need to stop and pause and bring myself back to the present through the breath. I'm learning not to fight the things that are beneficial for me. - a sense of choice/agency/self-determination; Gives me the courage to do what I know I ought to do to help myself. And to encourage a different quality of self-discipline – one based on kindness to myself. - being happier, more content Being able to increase my enjoyment of the small things and appreciate this more. Appreciating people's kindness, seeing more opportunities to be grateful.

Now, I am going to include A sense of choice/agency/self-determination; Facing my fears; Developing coping strategies; Hope; Compassion; Increasing self-understanding; Being happier, more content. Cultivating gratitude and appreciation - having the opportunity to learn, to practice, and deepen my understanding of my relationship to this, ie what makes it possible and what gets in the way, recognising this and then choosing to work through it; and then the ways in which my whole life benefits from it. Resilience - this builds resilience – knowing that you have choice, and that things will pass. This is why I'm now including 'Hope'. Facing my fears - bringing myself back to the present means that I face just what is happening now without being overwhelmed by my imagining what might happen in the future. Acceptance. - is part of this process

Acceptance, hope, and compassion have become more and more relevant and even achievable in ways they weren't before. Working with them has made such a difference to my life. Determination has improved – the more I practice the more determined I become to keep up my practice. Being happier, more content I'm noticing more joy in life - taking more time to enjoy the moment. Living in the moment/ being more present. This has been key for me. It's become a place of refuge when I find myself caught up in rumination or catastrophising.

Developing coping strategies the pacing diaries helped me see where I need to think and behave differently. I would like to spend more time doing this. Acceptance I am more accepting of the situation and feel less driven to 'finish' things as I may only have a short time to live without severe disability. Compassion feel I have become more compassionate towards myself, esp when I start driving myself. Not letting Parkinson's dominate my life The emphasis has changed to trying to incorporate it positively into my life through mindfulness. That I can see myself, and can be seen by others, as someone who can contribute to the wellbeing of my friends, and family, my community, - and myself. I can see

myself being able to do that now whereas before I was despairing that I might not be able to. Learning to manage my fatigue: see above re being driven and practising self-compassion.

Facing my fears: moving forward I would like to overcome my reluctance to do certain things (like go out in public) slowly, but probably a bit at a time. With my Parkinson's I feel vulnerable and find that I avoid feeling exposed. The other desired responses are on the back burner given the overwhelming amount of anxiety I am currently experiencing.

What have been the most interesting aspects of the Breathworks course in relation to your personal understanding and experience of managing Parkinson's Disease?

The idea that you don't have to react, that you can choose how to respond. Becoming more aware of potential secondary suffering. More emphasis on living each day with appreciation and openness.

Finding out about the distinction between primary and secondary suffering. The metaphor of the black wolf and the white wolf representing negative or positive thoughts/behaviour and which wolf thrives depends on which one you feed. Rosetta study pointed out the importance of social connection to our mental and physical wellbeing.

Helping me think more about what my triggers are, and using the breath to deal with it. The content and information that the book contained was both interesting, useful and practical. Finding out more about breathing and how it works on the body, and the hormones and then experiencing it in the practices. I have been finding that breathing more deeply has an effect on how I feel – calmer, more peaceful. It's been a great resource. Also establishing a regular practice and experiencing such a change in how I'm able to live my life.

The meditations have definitely helped on some level, although I can't say why. The whole course has been that way for me. The group and how we were together was an important part of what made the change possible.

One of the most beneficial features of the course has been the pacing diary. Which has given me the opportunity to practice what I've been learning – like actively practicing self-compassion and self-care more. The other thing is the difference understanding secondary suffering can make. So now I'm better able to accept the primary suffering without making it many times worse by spiralling into negative thinking.

Listening and learning from other people's experiences in the group. Just knowing that you are not alone. Learning to use the breath. And being with people who understand and are on a similar journey

The pacing diary, the concept of 'boom and bust', 'thoughts are not facts'. Realising that pain is fluid and that I am not stuck.

To make plans for enjoyable things – getting them into the diary. Learning to manage stress better.

I didn't expect that mindfulness would have this much power/effectiveness or that there was so much science backing it. And fascinated to learn that it is possible to re-wire your brain and all the science around that. This gives me precious optimism.

Is there anything (positive or negative) that you didn't expect when you started the Breathworks course?

Lived up to expectation. The way the group came together to provide such great company, support, and how we learned from each other. How nice it was getting to know everybody. Being able to share experiences, finding we had many things in common, and being interested in the ways that they were different. It was engaging and motivating.

I didn't expect it to be so effective. And found that the shortness of the practices were very important for me to feel I could manage them, and often found that I went on listening to more of the audio track and practicing for longer than I expected.

I didn't expect it to work. The group aspect of the course was much better than I initially feared.

I didn't expect to learn so much about how our thoughts can affect the quality of our daily lives. Nor did I expect to find how much there was in the book that applied to me.

I didn't expect that the breathing and stopping; and the pacing; and the interaction with the other members of the group; to affect me so positively.

The extent to which it has become part of my life.

I didn't expect that I would move past my resistance to practising, to actively wanting and enjoying my practising.

I thought this course might be similar to the MBCT course that I did previously, and it proved to be quite different. I now understand better the purpose of the meditations. The book makes that clear by backing it up with the science that's involved like the changes in body chemistry.

Is there anything else you would like to mention about your experience of doing the Breathworks course?

Definitely helped calm anxiety. Made me much more self-aware, e.g. when I start shaking, I am now more aware that I am tense and then I can breathe, give myself up to gravity or find other things in my toolkit. Meditations re-energise me when energy levels are dropping. What's important is how this increases my feelings of agency – I have choice.

Very happy that I did it and would like to do some more.

I'd like to do it again.

The fact that I found people in the group open and receptive, committed, and relatable, was a boost, a support and mutually strengthening.

When I started the course, I didn't know what to expect and am so pleased that at the end of the course that I feel like I'm just beginning. I feel much more open to the possibilities offered to me through mindfulness. It has been a very clarifying experience. The compassion of others and how it works both ways.

Being part of a group and how supportive it was made a big difference to how I progressed in the course. Feeling valued, feeling able to contribute. There was a strong sense of community and connection. To begin with, found it difficult on zoom but as you got to know people this changed. I would recommend that people be encouraged to come online earlier to get to know each other. I valued the variety of people and what they all brought. The

importance of making the practicing of mindfulness as much a part of my day as taking medication and doing exercise.

I very much appreciated meeting others on the course, their company, their support, and learning from and with them. It drew out my understanding seeing how each of us responded, in our own different ways, to our condition and to how the mindfulness was taken on board.

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