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 since the start of Covid, March, 2020, but in particular, the six months between November 2020, and April 2021. Its aim is to start a dialogue 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, Oxfordshire Community Foundation, and the National Lottery Community Fund.

There are two parts to this report. **Section one** (pages 1-3) provides an overall view of the project as a whole. **Section two** (pages 4-13) contains the responses of the participants taken from their Individual Learning Plans at the end of the last 8-week course.

A brief history of the first six months

The Mindfulness for Parkinson's Project started after the 8 week trial period which determined that there was a demand for a follow-on refresher/ maintenance programme for people with Parkinson's who had completed an 8-week mindfulness course. After running for a few months, Covid hit and forced us online. Moving to Zoom was surprisingly liberating- it allowed us to go from meeting 3 times a month to meeting 3 times a week. Eliminating the need to travel outside of the comfort and safety of their homes removed one of the biggest obstacles to participation that people faced.

Through word of mouth, and referrals from the Parkinson's nurses, physiotherapists, and the local Parkinson's UK website, the group grew to include people that didn't have previous experience of mindfulness. From this point on, we established a pattern of welcoming newcomers to the group with an introductory session followed by a number of sessions where they were able to experience a full range of mindfulness practices. This allowed them to ease themselves into mindfulness, to give them time to see if it was for them or not before committing to the more structured programme of the 8-week course we ran in May and June. You can find the participants response to this first 6 months by following this link: https://oxfordparkinsons.org.uk/documents/mindfulness/covid-safe-mooring

Preparations for the next part of the Programme

In the autumn 2020, we received a small grant from Oxfordshire Community Foundation which gave us time to set up a participant steering committee, and a group of people who we grandly called our Advisory Board which were in fact a number of individuals who very generously offered to be 'at the other end of the phone' should we need help and advice. With this in place, and working with the steering committee, we were able to lay down the foundations for the next phase of the programme. 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. The programme was promoted; new participants attracted; introductory sessions ran; in preparation for another 8-week course to be run. By November, 2020 we received a second six month grant from the National Lottery Community Fund to start the Programme.

The next six months

In November, with participants who were still largely drawn from the people who were veterans of the first 6 months, we started our second 8-week course, which we ran on 2 days of the week with the third day being reserved for a 'deepening and widening' drop-in session. And then in February 2021, we started another course with newcomers. Both courses used the Breathworks 'Mindfulness for Health', a book which won the BMA Popular Medicine Award first prize for 2014. Previously, we had used the Mindfulness Based Cognitive Therapy for Life, which is aimed at the general public, whereas this course targeted people with chronic illness much more directly.

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

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

Overview of the 8-week course in particular

The Programme has used 3 different mindfulness courses with people with Parkinson's, and the Breathworks course has been by far, the most successful. And it's not just the fact that it was targeted for people with chronic conditions, but that both authors of the book, Vidyamala Burch (also the devisor of the course) and Danny Penman both lived with severe and chronic pain. That they spoke from lived experience was palpable, and its effect compelling, and as a few of the participants commented 'inspiring'.
As the comments from the participants can bear out, there were 3 features of the course that can account for its success :

*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.

Also, what is remarkable is of the number of people who strongly identified with the statement "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". Of course it would be impossible to try to quantify the indirect effects of the course, but what is noticeable is the number of people who, by the end of the course, were sharing their mindfulness with family and friends, or who had become much more pro-active and engaged in their Parkinson's communities.
For an in depth look at the findings of the Individual Learning Plans please see Section Two

The mindfulness programme more generally

The Mindfulness for Parkinson's programme has been unusual in that it has been able to run three, one hour sessions a week for pretty well over a year. Many of the 47 people that have been engaged with this programme have been coming since March 2020. This was made possible by our funding and being able to go online.

The project worked with the participants to make the programme as accessible and relevant as possible. This was achieved through:

* Going online – this eliminated one of the biggest barriers to people's engagement with this programme – the restrictions, stress and uncertainty people with Parkinson's face when finding the time and the transport to attend the sessions.

* Developing and delivering a programme that participants found supported them with anxiety, and depression; increased a sense of acceptance, resilience, wellbeing and agency; and eased isolation.

* Zoom sessions allowed for much greater participant involvement in shaping the programme in terms of content, frequency, and length of our sessions.

* The community that came together, meeting three times a week during the long months of Covid, was one of the programme's accomplishments most valued by the participants. There could be openess, and mutual understanding, and with this support, mindfulness practice could be learned and integrated in a deeper way, contributing to people's ability to meet the challenges of their lives during Covid.

Lack of motivation is a recognised symptom of Parkinson's; a number of the participants acknowledged, that it was this community aspect of the programme that kept them going.

The essential role of Funding

It was the receipt of two, six month grants from the National Lottery Community Fund that have made this Project possible. . It has meant that offering this programme has avoided being transactional. It has meant that money has not determined in any way whether someone was able to attend or not. People have not been excluded for lack of money.

This funding has given this project the time, freedom and independence to develop this unique programme, in direct response to the opportunity to learn from and work with the Parkinson's community.

It is often funding more than any other factor that can determine the content but especially the length of a mindfulness programme. Typically, a programme made possible by public funding is limited to the 8-week course, most of the research that has been done is based on the 8-week course. Even when it is recognised that participants could benefit from a longer exposure, it has largely been money that has held this back. Courses offered privately, can only be taken up by people that can afford to pay £250 - £300 for the privilege. It is very rare for there to be a mindfulness programme, developed for a vulnerable population, with this degree of coherence and continuity, over a period of this length, at a time of national crisis.

An exercise in Gratitude

We would like to acknowledge and thank the people who have contributed

First, and foremost, the generosity, spirit, and commitment of all the participants.

The Oxford local Parkinson's UK - and in particular Sally Bromley, (only just recently) the past chairman, and Mark Jennings, the current chairman.

Michel Hu Consultant Neurologist

Jo Bromley, and Nicola Findlay, Parkinson's Nurses

Sarah Wheatley, Exercise Specialist, long term conditions

Professor Chrystalina Antoniades, Associate Professor of Neuroscience,

Dr Niels Detert. Consultant Clinical Neuropsychologist.

Dr Simon Prangnell. Clinical Neuropsychologist.

Dr Sean James Fallon, Research Fellow Bristol Medical School

Section two

Participants' responses

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.

The Primary Issues/Symptoms

The primary symptoms most frequently listed that were shared in both groups were tremors (7out of 10; 4 out of 7) and fatigue (6out of 10; 2out of 7). It was commonly found that meditation could directly calm the tremors and the feelings of agitation that accompanied them. One of the skills that the course taught was learning to pace yourself. Many people found that this had an impact on their fatigue. With the other symptoms people's reports were more complex and less attributable to one thing in particular, but seemed to be an affect of the experience of the course as a whole.

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

Stiffness: I've noticed that with more acceptance, my ability to think intuitively about how to deal with the stiffness in my arm has opened up.
Sleep: pacing diary has helped with the quality of sleep ie it allowed me to see that I need to go to bed earlier, and, accepting (with more compassion and kindness) that I might not sleep, rather than fighting it. Cognitive difficulties (memory, confusion etc)***;*** and slowness, could be seen to bear some relationship to the secondary symptoms: anxiety, panic and loss of confidence. With an improvement in my ability to manage the secondary symptoms, the impact of theses 2 primary symptoms has softened.

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I've started to look at the affects of some of the primary symptoms as something that can change moment-to-moment, esp pain. and not see it as an unchanging block. This can lighten the effect. I notice that while I'm doing a practice, because I'm lying down, the pain goes away, but after the practice, the feel good factor, feeling more relaxed, I find it easy to imagine that I'm being lifted by the increase of lovely hormones like oxytocin, seratonin, endorphins etc and that perhaps they might even buoy up my dopamine as well. I find that this is a very powerful tool for me.

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Pain the breathing has made a difference in my ability to manage the pain, esp at night. Fatigue**;** the pacing has made a difference with fatigue, and I now know better when to stop.

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I'm more self compassionate, not so demanding of myself. Tremors **-** learned to accept it more and no longer feel like hiding it. fatigue - learn to manage it, more sensitive to what I need.

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They are all still there but again, I'm experiencing a far greater acceptance, and knowing that they may be permanent . Many of these 'secondary' symptoms I experience as primary, none the less I

can learn to deal with them. fatigue accepting it rather fighting it – and learning how to work around it. and learning to relax when I'm off meds .
sleep using mindful breathing to manage an over busy mind. loss of dexterity doing something positive about it – giving myself time to work with it, being patient. Putting myself first not feeling guilty about not doing chores instead.
slowness (mental or physical) accepting it and not worrying about other people noticing it

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I am learning to see some of my symptoms differently, for example my slowness gives me the opportunity to stop, to pause, to observe everything around me and myself. Giving myself more time and appreciating it.

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My feelings about my symptoms have changed. I'm feeling more motivated to be more pro-active – exercise for example and of course mindfulness. There are a few practices that I can now draw upon that can change an almost physical sensation in my mind – like a fizz which I can sometime imagine must be brain activity which is some how dysregulated. Or more ordinarily, can recognise worry or anxiety before it gets a hold. I can sit back quietly and very kindly enquire of myself – what's going on? what do I need now? Which could be sitting quietly and breathing. Fatigue - I'm managing my time differently so that I'm improving the quality of my sleep.

Secondary Symptoms

The symptoms like anxiety/panic, low mood/depression, lack of motivation could be seen as primary in Parkinson's rather than secondary issues ie- ones "which could be said to result from the mind/body's response to the primary ones". The decision to list issues as secondary rather than primary in the end was pretty arbitrary.

Here there was an interesting difference between the 2 groups in their choices of of secondary issues. Anxiety (8/10; 3/7), Independence/dependence (2/10; 5/6), Lack of Motivation (2/10; 4/7), Frustration (6/10; 3/7). Also, it was seen that although there were changes in these issues over the period of the course, these changes were also influenced by what was going on in their lives more generally esp with Covid, or change in life circumstances. Often what seemed to change here were perceptions often arising out of insights which then led to skilful action/coping strategies.

anxiety; rumination which fed into anxiety, and not getting physical symptoms of anxiety , heart racing, breathless - by using mindful self-care. low mood; improved more sensitive to what I need – ie exercise. rumination; much much better, largely due to no longer working. frustration; more accepting

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anxiety; accept but don't give in to it – I don't stop/avoid doing things that make me anxious. low mood; noticeably less frequent, learning strategies to manage it by do things that uplift me (things that give me a sense of warmth) loss of confidence,; less confidence in what I do but being more in touch with being confident in who/what I am. And what I have learned/learning
lack of motivation that can result from loss of confidence is no longer relevant

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The course was clearer to me so – I've worked hard to work with the pain rather than against it. I was impressed with the varied meditation practices, which I've used extensively, often involving my wife.

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Yes I have noticed a change in my attitude and perspective over the time of the Breathworks course, especially in my secondary symptoms category. I am more accepting I think overall of my moments of low mood or anxiety and of my moments of perceived loss of physical "independence". I see them now more as a natural process that is understandable in the context of what I face physically daily and as a period of adaptation and transition as well.
I accept more that it is sometimes really difficult for me physically and emotionally to bear all the recent worsening and complexity of my motor symptoms in the last six months, and the addition of new symptoms - especially freezing on the spot, many times a day, in addition to the worsening of my shaking to my whole body nowadays.
As a result, I am learning to be kinder towards myself, which often means to learn to rest more and more often during the day, to plan times during the day when I can listen to something or watch something for example -at times when I can't walk, and shake too much to use my hands either, and am then "stuck doing nothing"- that is when I find an auditive or visual distraction very useful and welcome .
I am also learning to be much more patient with myself at times when my body is " in lockdown" and to find strategies -apart from trying new medical treatments - to cope with these often huge and debilitating fluctuations of my motor symptoms and my physical abilities during the same day- which means practically to develop new ways of accepting and coping with this new reality of myself. It is very much a learning curve and a bit of an experiment also on what works or not, at a given time. …I do, however, have more confidence that I can develop coping strategies- trying 'mini-meditations' in times of stress to try and break into the stress and pause for a moment, then start again from a calmer base.

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…<u>Frustration;</u> mainly with tremor - here mindfulness helps to work with this esp self-compassion and appreciating the good that is there

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No change in physical symptoms, but what has changed is the degree to which I'm able to accept the symptoms. As a result I'm not getting so frustrated and I am better able to derail the secondary responses before they kick in. This means I don't enter into the same unthinking negativity and resistance. It doesn't define me in the same way, I am more a person that happens to have Parkinson's rather than a Parkinson's 'sufferer. I still have good days and bad days but no longer feel so defeated by the bad days. I can accept them and not feel that I should somehow be able to make a better go of it. All in all, the weight of it (having Parkinson's) sits lighter. The stress and anxiety can lighten

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Rumination – first recognising it and then choosing to respond to the situation differently. Isolation now, this is due more to covid, but again I'm choosing to be more pro-active and creative in how I reach out to friends and family. And if I start to shake with serving wine or tea I now feel fine about asking for help. I've noticed that people can get anxious when they see me shake, but I now know that I can't allow this to limit what I do in their presence. Frustration with people not responding to my situation as I would have expected./needed. Now that I feel more capable of looking after myself which gives me more independence from other people's reactions, I can see more clearly/compassionately why people are the way they are.

Frustration; beginning to learn that pacing myself can ease my frustration when I want to do something before my meds kick in

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Isolation; I've become more aware of feeling isolated compared to how engaged I was previously, it' an adjustment I'm continuing to make. Independence/dependence; not finding either of these choices such an issue now, largely to do with how I am coming to understand myself better - as I am now.

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Lack of motivation; I'm finding that I'm more motivated to contribute to the local Parkinson's group. Loss of confidence is changing. Frustration; has reduced possibly because I'm becoming more accepting of the Parkinson's and am more patient.

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Lack of motivation; can often arise when I feel I'm not left to be responsible for my own welfare. Independence/dependence; this is an ongoing issue. Other -concern for partner; and how she is trying to manage the situation. The mindfulness course has given me the opportunity and confidence to suggest that my partner might benefit from mindfulness as well.

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'. *And once again there is convergence between the 2 groups choices. Developing coping strategies (9/10; 4/7), A sense of choice, agency, and self determination (5/10; 5/6) That I can see myself, and can be seen by others, as someone who can contribute to the well-being of my friends, family, community – and myself. (5/10; 4/7). However, there is an interesting divergence with cultivating gratitude and appreciation (5/10, 0/7). This could be accounted for by the fact that the first group had a greater experience of mindfulness where the value of this notion had been explored and experienced. Compassion hadn't been included in the first iteration of the ILP, but by the end of the first course, the participants suggested that it should be. Not surprisingly, the second course had only one person out of 7 make this choice. With both groups, acceptance received little notice (1/10; 0/7). By the end of both courses the change was striking. As you will see, compassion and acceptance featured in almost* *every response. And of course the choice* 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 *is central in most people's responses, and is particularly strong in the second group.*

I'm now including Cultivating gratitude and appreciation; (see below) A sense of choice/agency/self determination; recognise the opportunity to make more choices. Acceptance; see other comments, but will add this has been one of the more challenging aspects of the course, but possibly the most fruitful. Compassion; ; to myself was difficult, but once I experienced it quite physically it then began to make sense. Increasing self-understanding: increased so much more than I expected.

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Developing coping strategies ; learning to use the breath to work with disruptions during the night to help me get back to sleep. Any physical discomfort that arises, I can use the breath (breathing through the area) to ease it. I'm noticing my breath more often – when I'm walking for example. Facing my fears; the material on this course has been challenging and revealing and at times leaving me feeling vulnerable and overwhelmed. But I'm left feeling more positive about facing these things, and when possible, accepting that this is where I am, how I am, at this moment… Compassion; all the above is made possible by, or is an expression of compassion…. Feeling at home in my body; feeling like I have more insight and skill to respond to myself as body. 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 . Being in this group has allowed me to feel that I have had something to contribute .

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Developing coping strategies ; am more strategic with what I can and can't do. Use my breathing to help get off to sleep. A sense of choice/agency/self determination; accepting things as they are allows me to be more aware of choices I could make, as I become calmer. Feeling at home in my body; can be tricky when your body can change from day to day, but I feel encouraged to be patient and keep working with it as best as I can. Not letting Parkinson's dominate my life; that's improving. 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; the course has helped me look outward and realise that there are many small things that I can contribute to the people around me and I find that very fulfilling.

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Developing coping strategies; being able to use the practices esp the body scan to relax and improve my mood whenever I recognise a need to do so. Cultivating gratitude and appreciation; of small things that I might not have noticed previously, can bring such delight. Resilience; although I can't say why, I feel more buoyant generally. Facing my fears; I'm a bit more prepared to think about it than I was before. Acceptance; this has been a theme that has run through all of the course and seems to be the foundation of most of the benefits I've experienced. Compassion; and the same could be said of the compassion. Relaxed and calm; I could say that I'm feeling more relaxed and calm and at home in my body as well. - 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 ; this has changed, I have become much more engaged with the local Parkinson's community which makes me feel good because I can be useful and make a difference to people

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Cultivating gratitude and appreciation; during the course I began to experience the value of this, and the course itself, the way everyone was participating were some of the things that I appreciated and felt grateful for. - Acceptance; given an opportunity to think about acceptance and all it's many faces. Hope; in the book there was a lot of talk about hope that I found useful. Compassion; again it was in the book and in our discussions. This meant that I could see the importance/relevance of it in my own life. Encouragement; received a lot of encouragement from the others, which of course made me feel good. Determination; I chose this as a mark of my commitment to the course and to the others. 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; I hadn't thought about this before I did the course, but now having participated in the course, with the group, I found I was able to contribute, which felt very gratifying, and worthwhile. Increasing self-understanding; all of the different aspects of the course contributed to this, as well as Being happier, more content

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cultivating gratitude and appreciation; practising gratitude on a needs to basis has made a difference to mood . a sense of choice/agency/self determination; -before I limited myself by making unrealistic demands on myself. Self-compassion - which made me open up the choices and was more congruent with my Parkinson's and my life in general, where I feel more like myself, more joyful, lighter, freer. - relaxed and calm now I have more choice and can manage tension differently. - 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 partly fearing that I would lose that when I stopped work, but linked to my general increase in wellbeing I find myself more open and available to people. (further choices)*- increasing self-understanding* greatly improved *- being happier, more content - compassion* **.** *A*ll the others listed I have a deeper understanding of and am more able to work with them.

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Developing coping strategies **;** esp mindfulness practices and using them in a way that I've found works for me (eg 2.30 in the afternoon when I am both tired and off meds – helping me to relax and feel positive). cultivating gratitude and appreciation; was already there but the mindfulness practice has sharpened it up and encouraged me to put it into practice more – "treasure of pleasure" has helped to nurture an attitude of appreciation throughout the day. Appreciation of people as well as other things.
a sense of choice/agency/self determination; includes the choice not to do things I would automatically have expected myself to do…Instead, giving myself time and space to see what may emerge - relaxed and calm I find mindful practices are a highly effective aid to relaxation. For me this is about changing from being predominantly task centred to being people centred. Aiming therefore not to achieve more tasks in a day but to structure my days and care for my own health and wellbeing so that I am available to respond to the needs of others and to be positive, awake and able to smile rather than being tense and anxious or asleep.

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Cultivating gratitude and appreciation (new); resilience; with the change in my daily routine/grind has allowed me to reset. Esp with the introduction of mindfulness practices, it felt like a new page . - not letting Parkinson's dominate my life; feeling determined that I will be able to stop 'letting Parkinson's dominate my life'. - 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 I can contribute to the well being of others if I am calm and positive.

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Coping strategies - Using 3 steps meditation, and mindful walking helps when going for walks. Also not trying too hard in the mornings just accepting I can do very little till 11 or 11.30, or after 4 or 5.

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Staying relaxed and calm has now increased relevance for me because as I increasingly experience more frequent and intense shaking and freezing. To begin with it was like facing a tsunami and having to gather up the scattered pieces of my body to try to feel whole again. So now, it is still unpleasant but I am learning to keep as calm and collected as I can. By knowing that this is momentary, and that in the midst of all this tsunami there can be calm; that my spirit can stay calm, and remains whole, and there to help me, and to hold the unity of my being. So being able to accept these wild fluctuations I am able to maintain 'feeling at home in my body' having at first felt quite the opposite, that my body has become frighteningly foreign.

My anchor through this has been practicing gratitude and appreciation. Enjoying simple things that are accessible, looking out the window, my family, my bunny, a warm cup of tea. I am choosing consciously to engage my attention in what helps me, gives me pleasure, reaffirms my wholeness as a human being, and that my life is 'not letting Parkinson's dominate my life'.

By learning to observe myself I'm becoming more sensitive to what depletes me, esp. as I become more tired during the day. Emotions are closer to the surface, there are times of feeling raw. I can become over-stimulated more quickly by sounds, intensity of colours, too much activity. Time has become more precious.

Learning to ask and accept help from others. This has been very difficult for me. So being able to this balance this with my ability to exercise my 'sense of choice/agency/self determination' is an important area of learning, interacting with other people. I know, that like the physical symptoms, they too will ebb and rise. This is where patience helps. This has been a steep learning curve – I am not naturally patient.

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In addition to the original ILP responses (cultivating gratitude and appreciation;
- resilience; - a sense of choice/agency/self determination, - 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) post Breathworks I added 'acceptance' 'determination' 'not letting Parkinsons dominate my life' and self-compassion. I've put these into practice through recognising more deeply that I have ongoing choice in how I react on a daily basis not just when feeling positive. I've put into practice through active curiousity, willingness to find out more about PD i.e. not shying away from some of the 'difficult' stuff, and keeping gratitude/appreciation to the forefront of my experience whenever I can and particularly when sensing frustration arriving.

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Developing coping strategies ; As previously written, nipping things in the bud, taking time to ask myself what's needed now, taking more care around sleep. I've found that working with the breath has been such a valuable resource. - cultivating gratitude and appreciation*;* more aware of the beauty all around me. Try to live in the moment, and not try to sort out the world - 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 (new); After the grief/shock of losing my partner and then being diagnosed with PD, finding my feet again, I now feel more able to do this, and of course this contributes to my own sense of purpose and worth.

We also asked

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

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

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

Benefits of mindfulness more generally

" moving towards accepting the tremor was a game changer. And generally realising that I don't have to react or think the way I do – I can choose"

" One of the most interesting observations for me is the surprising strength of the results from mindfulness. That it really is possible to accept things and be more content"

"In essence the course has increased my
confidence in my ability to make changes in lifestyle in response to changes in my PD"

" It has been excellent in helping me to keep a focus on how to best live with Parkinson's and given me tools to deal with the more difficult moments experienced so far".

"It's been a revelation to me and been a very useful aid in coping with my life as I find it now. It's made me much more appreciative of my life."

" How lucky I feel that I've been able to do it, and how valuable I've found it. I wish that mindfulness was available more widely for PwPs"

" I feel moved/ very motivated to share this and learn more and more."

Better than expected

" It was more demanding that I expected but worth it."

" I didn't expect it to be so good."

" I started the course being somewhat sceptical, and have been more than pleasantly surprised by how good and useful I've found it"

The importance of strong, warm, heartening attitudes/feelings

"The sustained focus on kindliness and compassion, both for yourself and for others (and the link between these two)"

" Experiencing how important attitudes/qualities like gratitude, appreciation , kindness and compassion are to feelings of self worth, well being."

"Also compassion – to oneself and then to others."

Benefits which could be said to be specific to the Breathworks course

"The pacing diary was very useful to allow me to stand back and view my life in perspective."

"The parts of the course which deal with the scientific understanding of our neuro-biology and how that impacts our ability to change. For me, this gives mindfulness a solid foundation"

"The combination of accepting the negatives and enjoying the positives rather than fighting the negatives and failing to notice the positives. Learning to accept calmly the combination of negatives and positives (the yacht)"

"The emphasis placed on seeing the difference between the primary and secondary symptoms and how exercising your choice can improve your experience of the condition. The way she talks about dealing with pain was particularly useful and relevant*,* and also inspiring."

"I was interested in finding out about the correlation between the neuroscience/neurology and the Parkinson's"

"The most interesting aspect of the course was the scientific evidence that meditation could cause physical changes in the body which can lessen some problems caused by PD – for instance secondary symptoms can be controlled with practice and dopamine production increased".

"The "wolf" story and the "Roseta" study were both unexpected and extremely relevant and helpful. Both coincide with my Christian understanding of how to live your life and the importance of an open and supportive community."

"I can't help but be inspired by the lived experience of the people who devised this course – it gave credence to what they say. It made it more engaging"

"I was also surprised how relevant the course was to PD. An earlier course I attended seemed not to have much bearing on PD".

"Which wolf you feed" really delivered a message that I have found increasingly relevant"

The role that the growth of a strong sense of community played

" The strong sense of community, feeling welcomed, is one of the largest contributing factor to the success of this course - the ways in which people have allowed themselves to be vulnerable."

" Surprised by how much easier being on zoom makes getting to know each other and the extent to which we have developed such a warm sense of community."

" Being engaged with the others on the course made being engaged (showing up/doing the practices) with the course so much easier".
" It has been good networking with other sufferers"

"I've got great encouragement from sharing the actual practices with the others in the group - the experience of doing the course with people experiencing the same issues and the feeling of community."

" Other people on the course, a supportive group".

" I've liked the sense of continuity and building on the foundations the course offered. Enhanced by the sense of community, discussion and shared experiences from other people – the connectivity and communication."