

Mindfulness for Parkinson's Project – Report

May 2024

Azizë Stirling

This document reports the activities and findings of the Mindfulness for Parkinson's Project between May 2023, and April 2024. This will be a shorter report than the 2 previous (May '22. May 23) for a more detailed account of the background please refer to them.

Our aim has always been to make this programme 'free at the point of access'. This programme runs continuously, year-round, but runs more actively during the 6 months when we are funded (National Lottery). This is a time when we can run the 3-session introductions to mindfulness. This can be followed by the BMA award winning 8-week course 'Mindfulness for Health'. Now we have a choice of 2 follow-on 8-week courses - Mindfulness Based Compassionate Living, and most recently, a course, just developing, (from the same people that developed Mindfulness for Health) HEALS. Added to this are deepening sessions, investigative sessions, and weekly drop-in sessions, and mini- retreats.

This past year we have been able to offer:

3-Session Introductions:

Are designed to introduce mindfulness and its possible relevance to people affected by Parkinson's. this includes People with Parkinson's, friends and family members, the health professionals that care for them. The overall aim is to give people time to discuss, experiment with and absorb a variety of the key mindfulness practices and the thinking behind them. We have held one for People affected by Parkinson's, another for Parkinson's Physios, and a third for Parkinson's Nurses.

Mini-retreats: all of our programmes are delivered on-line with the exception of the Mini retreat. Here we meet up for 4 hours to gently go through mindfulness practices, often out in nature. We had 4 this past year.

Deepening sessions are for people who have completed an 8-week course and wish to deepen their understanding and practice mindfulness. It ran for 5 sessions

Investigative sessions: where we investigate issues that can affect people with Parkinson's and then look at ways in which mindfulness practice could be relevant. So far we've looked at breathing, anxiety, and sleep.

HEALS: is a longer course, running for 10 weeks, and provides structured, expert guidance to help achieve manageable, sustained changes in the areas of life known to improve health, and wellbeing such as nutrition, sleep, exercise, connection, and mindfulness. this course was so successful that people didn't want it to stop, so we continued by making a ½ hour slot for it following the weekly drop-in.

Weekly drop-ins: run all year round. During the funded period they can be run twice a week as it is rare to find a date that most people can make. Each session has 5 minute slot for social breakout rooms, then 10 minutes of mindful movement, followed by a meditation.

8-week course ‘Mindfulness for Health’.

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. We find that this course targets people with chronic illness much more directly. And this year for the first time, we were able to run this course for 5 Parkinson’s physios.

Individual Learning Plans: are used to collect qualitative data on this course. The ILP was drawn up by the community and reflects what the participants find most relevant. We find that going through the ILP process can reinforce and extend learning. And the written-up results can be used to inform the larger Parkinson’s community, especially the medical professionals.

Looking at the results of the past year’s ILP results, there were a few features of the course that stood out:

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 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”

Following on from this is people finding that their **experience of their primary symptoms had changed:**

“Stiffness - as medication wears off walking slows down - when I first experience in the morning, I now know to think ‘it will improve once I’ve taken my medication, and once I’ve started to exercise.

Pain sharp pins and needles - more generally a change in attitude, accepting it as it comes knowing that it will change. I no longer resist it in the same way

Loss of dexterity (eg hand writing) and even typing can be affected, preparing vegetables. Now, don’t worry about it. Accept it and can now see that my hand writing is better if I do short bouts of it, Have learned to work with it”

“Pain my attitude has changed I’m no longer so concerned about it and somehow this seems to have reduced the amount of pain that I’m aware of. Balance/mobility falling over, restricted how much I could leave the house. I’m less anxious than I used to be, but it is still an issue. But generally, I feel freer to leave the house.”

"Tremors if I work my muscles too much, but then I find if I do mindfulness with breathing and then softening key muscle groups esp in the face the tremor will ease if not go away completely. I have increased the time I do practices from just the morning to now include the evening. This has made a difference to the quality of my sleep. I can now use the breathing anchor meditation which can help with the stiffness by encouraging softening and letting go of tension.

"More accepting of the primary symptoms which results in less anxiety, and less fear"

"Anxiety has more or less changed with the changes I've made with the primary.

Discomfort/ uneaseful with the pain and the loss of dexterity, chores take so much longer - It's there from time to time but has changed now that I relate differently to the primary symptoms"

*it's emphasis on how to **work with acceptance in the context of self-compassion**

(accepting what we can, as much as we can, moment to moment, with a growing sense of kindness) and that with developing compassion for ourselves can come more compassion for others, and the way the two can build on each other.

"This can be a very challenging. Understand better that choosing to accept things rather than resist them as resisting them is fruitless, frustrating, and impacts one's sense of wellbeing...hadn't thought about being compassionate to oneself before and I found that illuminating"

"Acceptance - this has been key to the changes I have experienced. Relaxed and calm - tied up with acceptance, the more I can accept the more relaxed and calm I am,"

"I'm better at accepting what I can and can't do".

Another feature is 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.

"Compassion reduces the inner critic and learning more skillfull ways to look after myself. Like meditatating when I can see that I need it. And pacing myself is an important part of this."

"Fatigue, pacing has helped with this"

"The pacing has helped with looking after myself so I can avoid the stressful situations that can set off my symptoms"

"The pacing diary was very useful. It allowed me to take more control of my activities and their outcomes."

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

"Learning about the scientific basis for mindfulness processes. I found this reassuring and it gave me more confidence in the process."

2nd time around: this programme makes it very easy for people to do the courses more than once. The fact that it is free at the point of access contributes to this. The comments below illustrate how beneficial this can be.

"Treasure of pleasure really came to life for me second time round and really helped to shift any low mood that was present."

" When I was aware of experiencing discomfort it was here that compassionate acceptance became relevant.

During this second course, my understanding of this concept (compassionate acceptance) moved from just being a concept to something that became multi-faceted/dimensional. It became something I could experience differently in different situations. I no longer confused this with self-indulgence. But instead, it is absolutely essential to my wellbeing and that of others."

"Cultivating gratitude and appreciation. I value this a lot, it has made a big difference in my day to day living. The first time round I didn't appreciate the time we spent in the breakout rooms. It reinforced, supported and illustrated what I was beginning to understand about the 'treasure of pleasure' and self-compassion. And being reminded that 'thoughts are not facts' and all the many other useful constructive ways of thinking and behaving, leaves you feeling more full of hope. And not hope in the sense that you hope for something in particular, more of a brighter, hopeful outlook"

"The random acts of kindness exercise, second time round, showed me how important a vivid sense of connection to others was to my own sense of well-being. It's so important to feel that despite everything I can still, in small ways contribute to others well-being."

"I didn't expect to get as much as I did second time round."

Increasing a sense of connection and community

"The camaraderie was a big positive. It allowed for more than just a social kind of enjoyment but contributed and supported the depth and the relevance of our learning."

"Being able to see how other people benefited./ were benefitting esp in the people that had done the course before was heartening."

"The group came together quickly which allowed for good conversations to take place"

"I really appreciated the interaction with the others."

"The impact of connectiveness, not only with the people that I actually meet but with people I can imagine. It calms me down takes me out of the isolation that comes from thinking we are alone in whatever situation we find ourselves in. The sense of mutual support that there can be when people meet and can appreciate this. Especially true with the people on the course."

"...showed me how important a vivid sense of connection to others was to my own sense of well-being. It's so important to feel that despite everything I can still, in small ways, contribute to others well-being."