

“Mindfulness - a safe mooring during the Covid storm”

A short while ago the survey carried out by P. UK and Lancaster University came to our attention. They asked over 2000 people who were affected by Parkinson's, so not just PwPs, but their friends, family, and carers, about their experience during lockdown. The headline that appeared on the P. UK website was stark:

"Over a third of people with Parkinson's have experienced an increase in at least one of their symptoms during lockdown, according to a survey."

The symptoms included fatigue, sleep problems, stiffness, increased tremor, increased slowness of movement, and anxiety; with increases ranging from 26 -39%. But there was something that the P. UK article left out that the University article included:

"Increased caring responsibilities for family, friends and carers also had a negative impact. 68 per cent had taken on more caring responsibilities since the coronavirus restrictions started, 42 per cent said the restrictions were negatively affecting their mental health and 34 per cent their physical health."

As it happens, when lockdown started, the Mindfulness for Parkinson's programme was forced to go online. This turned out to be an enormous blessing. Without the restrictions of finding dates and venues to hold our sessions, we went from 2 hour meetings 3 times a month, to 1 hour zoom meetings 3 times a week. We began to talk about how this extraordinary frequency over a period of about 5 months affected the participant's ability to deal with their life through lockdown. In the end, ten people wrote down their accounts of their experience. There were people for whom lockdown was, in part, a time marked with positive change, where mindfulness was an important contributor to a positive, upward spiral. For others, where lockdown might have left them feeling isolated, or, without the structure they had built their day-to-day life around, the mindfulness sessions provided a new structure, a supportive community, and a sense of their own resilience and optimism. Here are a few of the statements:

(Note: 'Mindfulness for Parkinson's' is a programme run by Community Based Mindfulness and currently funded by 'the Community Fund'. If you would like to know more about our programme please contact Azizë Stirling 01865 790168, communitybasedmindfulness@gmail.com)

Participant statements

For my part I believe my sleep has been improved as a result of mindfulness. My condition has worsened but then it's a degenerative illness so I'm not sure it's Covid or not. My mental health has been quite good overall a combination of my general resilience complemented by the mindfulness sessions. *Frank*

The most obvious negative impact for me during lockdown was that my exercise classes stopped. I had been attending three or four classes every week (Zumba and Groove Aerobics) and I almost immediately noticed a deterioration in my balance, stamina and state of mind. My shoulder and forearm pain, which I strongly maintain exercise had kept in check, became noticeable worse. I also hugely missed the social side of attending classes too. I did continue with the one on-line class a week offered. I was also unable to continue with my 4-6 weekly massage which, again kept my shoulder and arm pain under control.

During this time, the physical practices which Azizë supervised as part of the on-line Mindfulness sessions did help to keep me a little active. I managed to recreate some of these on my own at home which helped keep my shoulder from seizing up entirely. I also continued to walk every day, often mindfully.

Generally speaking the Mindfulness sessions helped enormously as these provided much needed social interaction and a purpose to my day. I found the fact that regular sessions were offered gave me back a routine and structure. The sessions themselves calmed me down, lessened my anxiety and brought me serenity. They inevitably helped to re-set my clock. This was so valuable at such a difficult time. I feel I

could easily have been overwhelmed without this release valve. Being able to chat with people who were sharing many of my Parkinson's symptoms and experiences was reassuring and comforting.

Had these sessions not been offered on-line, I doubt very much whether I would have attended many sessions as the travelling would have been a challenge to me. It was so simple to log on, dial in and benefit from Azizé's expertise. It was also reassuring that I could likewise sign off at any time if I became too tired or too emotional to continue.

During lockdown, our family have tried to look out for one another – often necessarily from a distance - and with my specific health problems (not just Parkinson's) I am always on the radar of my husband and children. Knowing I had access to the Mindfulness sessions reassured them that support was available to me. That helped them to relax a little. I think they all noticed the negative impact the lack of exercise had on me, both physically and mentally but were encouraged that I had another source of help which could help me be resilient during this pandemic. *Trina*

In the week before lockdown whilst working in a primary school I felt unsafe in that environment. Once I had been told not to go in I felt safer.

I was in lockdown with my husband and daughter which despite the fear that I felt at times, we quickly slotted into a daily routine which was made all the more enjoyable by the warm weather. We managed to exercise at home well, and cycled or walked once a day. My husband initially took on the food shopping which wasn't a problem.

I found the zoom mindfulness classes gave me a focus for that day, I found myself looking forward to meeting up with familiar faces, especially as we all had the same condition. During these strange times the group felt supportive and strangely comforting. I felt this was perhaps because having to stop outside classes, meetings and work, this continuation of a group through zoom gave back some normality and structure to the week.

I felt that my family benefited from the mindfulness meetings also as the classes helped me to feel that I was still socially active in an otherwise isolating situation. *Sally*

My position is different from the other members of the group, of course, in that I am currently the only partner of a Parkinsons sufferer. I have never suffered with fatigue or anxiety so understanding how difficult these things can be for my wife has been a deep learning curve for me. By participating in this group and talking in smaller break-out it has really helped me to understand the condition more fully. I have enjoyed being a participant and although I am medically fit doing the regulation meditations and the 8 week mindfulness course have also benefitted me. We are both aware it is really important to keep mindful and not think too far ahead about how the condition could progress.

However, I was, and still am, conscious of the difficulties and stresses with the current situation re lockdown. In keeping with countless other people, the continuing uncertainties surrounding the return to normality exacerbate these stresses and anxieties for us all, particularly for my wife and others.

There is no doubt in my mind that the Mindfulness Zoom sessions have helped to alleviate difficulties. Face to face interaction has been temporarily lost of course but the regular meet ups have provided a focus for Parkinson's sufferers. Aply run by Azize they have helped to reduce the feeling of isolation and continue to be an invaluable forum for sharing feelings, symptoms and general concerns. Some group members joined later in the lockdown and were welcomed and easily accommodated with existing members. I hope this group can continue longer term for both of us and I and I would actively recommend other partners joining. *Anon*

I was diagnosed with Parkinson's 15 months ago. At that point in time I was experiencing muscle stiffness impacting negatively on my life in ways such as: difficulties getting out of chairs; difficulties turning in bed; rigid arms when walking etc; slow movement resulting in me taking a prolonged time to eat meals; a slightly shuffling gait; a stoop etc..

General anxiety about what was happening to me making it difficult in social situations and dealing with many everyday situations resulting in frequent tremors across my whole body. The result was that I did not want to meet people and generally interact with others. This was of great concern to me following retirement from a successful career in education that resulted in me finally being director of an international centre at the University of Reading for the last 10 years of my working life. I also had a senior national role in Rotary and was actively involved in community life. The situation worried my family greatly at that point in time.

Following clear diagnosis and the allocation of medical practitioners to support me, my initial reaction (and my family's) was one of relief and rather than begin a course of medication I gave myself 6 months to research the condition and available treatments and therapies. During this period I became more mentally stable with regard to the symptoms -even though they still impacted upon my life greatly. I decided that mindfulness was one of the tools that might suit me to deal with the progressive impacts of the condition, which was how I came to join Azize's group. From the start I found the networking opportunities with other sufferers invaluable as it helps to gain a perspective on the different circumstances of fellow sufferer's experience and build a knowledge base of how others face and cope with the condition. Plus it helps mental well-being to share experiences with those who you know are able to empathise with your feelings and thoughts about your world experiences.

Just prior to the COVID lockdown I began a course of medication (Sinemet) and within a short time began to feel multiple benefits from the drug including less slowness, more flexibility in my limbs resulting in greater self-confidence, a greater sense of mental well-being, less anxiety and reduced tremors. My regime throughout lockdown consisted of regular daily walks and fitness sessions with Kate my wife, gardening and zoom conferencing for mindfulness sessions with Azize and the members of the mindfulness group. This regime proved very beneficial to me and my sense of well-being increased. The mindfulness sessions in particular helped me to learn to live in and enjoy the present rather than dwell on anxieties of the future. Zoom was a particularly good format for meeting as it did not necessitate travelling and is easy to fit into the planning of a day. Each session has a different focus and increases the range of tools with which you are able to deal with the challenges of the present and changing landscape of the condition. Each session however is an opportunity to refresh the values and precepts of the practices of mindfulness enabling the accumulation of benefits. Without the regular programme and opportunities for sharing, the impact of the techniques would be blunted.

During the COVID period I have had limited support from medical practitioners. This however has not bothered me because of the regime I have developed and the support from the mindfulness group that has enabled me to manage the condition successfully to maintain a sense of positive well-being.

The benefits for my wife and family have been immense as there is less worry and concern for my immediate health as I am currently able to undertake a full range of domestic activity. I also have much greater social confidence again and have learned to accept and live with the changing levels of symptoms as they manifest themselves. This has allowed me to continue with a range of community activities in a confident way including being a chair of governors for a local school and continue as a councilor – a role I was considering giving up. *Anon*

Overall, the lockdown period has been beneficial for me for many reasons that I will develop below.

After the first initial bouts of anxiety and insecurity that I and my family members felt at the announcement of the lockdown period, we each of us started to settle into a new kind of routine at home. Myself, I quickly started, among several new activities on Zoom, doing Mindfulness sessions three times a week under Azize's supervision with our Parkinson's group. I quickly found those very beneficial for many different reasons and on several different levels.

I have done, in the not so distant past, two good eight week courses of Mindfulness with two different instructors but found, at the time, that I did not practise as much as I had intended to at the start, and had consequently not reaped enough long term benefits and useful mindful habits.

I had also been wanting to join Azize's sessions for a while but found that I was not able to cope with the driving to Oxford and back. So for me, having the sessions on Zoom has been an amazing opportunity, as it finally enabled me to attend her sessions, not just once a week but three times a week, which I would never have dreamt to otherwise !

I am 57 years old and was diagnosed with PD six years ago. My physical symptoms sadly have not improved particularly during lockdown. If anything they have worsened quite a bit as I shake much more than I used to 6 months ago and so feel more incapacitated and exhausted physically and more often in physical pain for longer periods daily and nightly than I used to.

I spoke to my neurologist recently and she, as a result, increased my current medication. My shaking is now starting to also reach my nape and my head and the whole of my left side as well, and, as I am left handed, it is naturally becoming a big worry to me. I also have some serious difficulty walking and driving, or merely functioning during periods of the day when I am feeling off medication. I notice daily that the Parkinson's drugs nowadays take longer to kick in and that their effects last less long than before, which is depressing and worrying me about the future. However, in this very far from rosy physical picture, I did find the Mindfulness sessions very beneficial to calm me down mentally and emotionally, especially during the scary shaking bouts I now experience on a daily basis.

I have been training myself to breathe into them in different ways, to try to relax and to concentrate on some parts of my body that do not shake, or to concentrate on or visualise other things or thoughts when I am about to experience a 'shaking type of panic attack'! I am daily testing one or two different techniques borrowed from Mindfulness, TaiChi, Qigong, Yoga and singing exercises to try to help myself to cope better with my Parkinson's. More often than not it works, even if it is still really difficult, and I also know that it takes practise, time, commitment, patience, humility and a good degree of creativity!

While not getting rid of my physical symptoms, it is helping me to look at them with more positivity, some degree of humour and less apprehension than before which in turn helps keeping the anxiety and depression at bay most of the times. I am learning to live in the here and now, to appreciate the present moment, to be more aware of my body's needs and to love my life the way it is now.

Just before lockdown, I also started talking once every other week to a psychotherapist about my physical, emotional and mental issues with PD and that too in combination with Mindfulness and everything else, has helped me to come to terms with the degenerative nature of my Parkinson's. Hopefully it has made me more understanding of other people's health issues.

The Mindfulness Parkinson's group has been an immense support to me during lockdown and it has been empowering to be able to sometimes voice really honestly and without any social barriers my difficulties and issues tackling my PD symptoms and being able to share experiences and thoughts with other PD sufferers has been invaluable.

My family, partner and two teenagers have been very supportive as well during the lockdown and my husband in particular (but also my psychotherapist) have commented several times how I seemed to be in a better place mentally and emotionally, how more serene and happier I looked and sounded during that time. During lockdown, my older son enjoyed training me daily to hit his boxing pads for about 10 minutes in our garden and we had fun together and a good laugh, often at my expense and about my poor physical performance. It was a great way to let go of frustration and tension and at the same time a valuable physical exercise!

During lockdown, I also started the new habit of taking daily photographs of my surroundings, nature and people, and found that I thoroughly enjoyed myself in the process ... and delighted in the slower pace of my daily life.

I am hoping that those wonderful Mindfulness sessions will continue on Zoom from September onwards as they have been so valuable on both a personal and familial level. *Beatrice*

My anxiety and loneliness were definitely made worse during my time of self-isolating. The regular meetings with others with Parkinson's was very helpful. With my friends and family I find that most of the time I feel the need to put on a brave face which can be tiring. The mindfulness calms me down, helps me sleep and also I enjoy each day as it is. Helps to stop me worrying about the future and make the most of the moment.

My family are pleased to hear I am getting support and were reassured as they worry about me living alone especially during lock down. *Sue*

I'm 63 and live with my partner Chris in Botley. I was diagnosed quickly in May 2019 (consultant, Dr Michelle Hu) and, having suspected I had Parkinson's earlier that year, I'd had a bit of time to research options. As a result I asked to be put on medication right away. I'm on Madopar and immediately it made a difference, easing muscle stiffness and pain and making walking and activities of daily living easier. My decision was fully backed-up by Chris who has been an immense source of support to me. Though a shock, diagnosis for me was a relief, and gave me something tangible to move forward with.

By July 2019 I'd joined the local Parkinson's branch and I continue to attend meetings. Throughout 2019/early 2020 I participated in a variety of local research programmes, joined a tai chi class, had a series of sessions with a neuro-physiotherapist, and continued with my own 'research' into living with Parkinson's. I've also helped provide feedback to Parkinson's UK on aspects of Covid-related information on their website and attended OxWAG meetings. My motivation for this? Trying to accept my situation as fully as I can, to learn from others, and be kind to myself instead of critical/anxious.

And then I came across Azize and the mindfulness sessions (mentioned at a branch meeting) just before lockdown. As a Buddhist, I was familiar with mindfulness from a different perspective but hadn't necessarily put two-and-two together about how it might provide another source of support for me! (When I was diagnosed I wasn't told about any local mindfulness sessions so hadn't done the 8 week NHS course that others have done – perhaps courses run less frequently now?)

I've found the mindfulness-sessions really beneficial in lots of different ways. Firstly (not in order of importance), I've been reminded of the need to keep practising/revisiting the variety of 'tools', attitudes and approaches that can help 'defuse' and tackle negative thinking. Secondly, the class has brought together a group of people, from different backgrounds but with a shared living experience, which has grown into a source of inspiration and support for us all. The regular structure has helped build this trust and, for me personally, helped me to remember my own personal responsibility towards myself and others. The gentle steering, facilitation and choice of content by experienced teacher Azize has provided many 'gems' in an atmosphere of support and honesty. It's reminded me of the need to take 'time-out' to stop and reflect on my life and life around me. Thirdly, I'm grateful for the unexpected benefit of a Zoom class making contact still possible and actually probably increasing participation across Oxfordshire.

I'm not aware of lockdown aggravating my symptoms overall. I know I've done more regular walking, and appreciated the sunshine and local green spaces. Anxiety has been present but the 'strange days' and flux of a Covid-impacted world makes this somewhat inevitable. Whilst Covid has reminded us of the fragility of humankind and our interconnectness it has also revealed how much kindness there is in the outside world. I'm aware that my own resilience has been deepened by taking part in the classes. *Jan*