

Adventures with Parkinson's: empowering Parkinson's patients to become active partners in research and treatment

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“We set out the what, how and why of moving individually and as a community, from being passive recipients of our healthcare, to being instead active collaborators involved in partnership with clinicians and researchers.”

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The relationship between people with Parkinson's and regenerative medicine is often ambiguous. As people with Parkinson's, we raise funds for research, we raise awareness of the condition and of the work to understand and hence slow, stop or cure it; but we are no longer seduced by the prospect of an imminent miracle cure. A recent paper by Barker *et al.* [1] concludes that *“as the ability to make authentic mid-brain dopaminergic neurons from stem cell sources improves, so does the reality of a first-in-human clinical trial in patients with PD. [But] only too often are exaggerated claims made, based on limited pre-clinical data and the desire to pass the financial and regulatory hurdles needed to get to clinic”*. As patients, we cannot live without the hope of a life well and positively lived. This paper explores how we approach this, and the role that we play in supporting regenerative medical research. We also extend an invitation to the regenerative medicine research community to continue and deepen this conversation.

In his 2011 Maastrich TEDx [2] talk *“From God to Guide”*, and his 2016 Edinburgh Parkinson's Lecture, *“The Future of Parkinson Care”* [3], Professor Baastian Bloem sets out the principles of participatory medicine, in which Parkinson's patients, researchers and healthcare professionals work together. In this article, we outline how the Edinburgh Parkinson's community: people with Parkinson's, including us as authors, our families and friends, have for some time now been becoming *“part of the participatory process”*. We set out the what, how and why of moving individually and as a community, from being passive recipients of our healthcare, to being instead active collaborators involved in partnership with clinicians and researchers. In the words of the Dalai Lama [4], we are recognizing that our long-term individual interest lies in the welfare of everyone in the Parkinson's community and beyond into the wider society. Throughout this article, we use the convention People with Parkinson's (PwP) to mean people or person with Parkinson's – for example both the singular and the plural according to meaning *in situ*.

Education is at the heart of everything the Edinburgh Parkinson's community is doing. We are educating ourselves as lay people in all aspects of Parkinson's and cutting-edge research into the condition. We are educating our health professionals, researchers and students about the lived experience of Parkinson's (this last with interesting and far-reaching research consequences for regenerative medicine, explored below). We are learning how to develop a quality of living that goes far beyond whatever our physical symptoms – or those of our care partners – might be at any given time, and sharing that knowledge and insight too with our health professionals.

The article introduces a wide range of activities provided by the Edinburgh Branch (nested within the wider context of Parkinson's UK) and examines how each activity contributes to and enhances the others, bringing very real benefits to everyone involved. We suggest three core principles, derived from a tested model of therapeutic relationship, to support individuals and the Parkinson's community in moving forward, and we reflect on the

conditions, the relationships and the qualities that continue to foster active collaboration between PwP, our healthcare professionals and the wider society. And finally, in a call-to-action, we challenge other Parkinson's research communities to create their own participatory processes.

Making the changes

This ongoing journey is not straightforward for anyone in the equation. Cultural patterns of patients' deference to their medical professionals, and the corresponding pressure on those professionals to 'have an answer' are deeply rooted, dominated by the 'restitution narrative' in which "*a person is not whole, not really able, unless one is 'cured'*" [5,6]. Unless each person in the equation changes, then the culture cannot change. The words that Bloem uses – partner and participator – are powerful when challenging old habits, and countering "*such mechanisms as 'remembering the old' and 'forgetting the new', that resist change'*" [7].

Education

If practitioners are moving from "*Gods to Guides*", then it is essential for PwP to move from passive patient to participating partner. The first step, we have found, is to understand Parkinson's and how it shows up, so very differently, in each of us, learning the difference between motor and nonmotor symptoms, finding out what the latest research recommends on how best to look after ourselves and manage our symptoms. Understanding what choices we as individuals can make, moves us toward an adult-to-adult relationship with our healthcare professionals and researchers, based on mutual respect, which itself encourages us to be more inquisitive and therefore more knowledgeable about our condition.

A key driver for this has been the Edinburgh Research Interest Group (ERIG) that had its genesis in the World Parkinson Congress held in Glasgow in September 2010. The members of the Edinburgh Branch of Parkinson's UK who took part in that Congress were inspired to organize a symposium in Edinburgh in November 2010 where they shared their impressions of the current state of research with other members. The enthusiasm generated was such that it was agreed to form a Research Interest Group. In July 2011, detailed discussions on the purpose of such a group were held by Branch members and other interested parties, in particular, Dr Tilo Kunath, at that time, a Parkinson's UK Senior Research Fellow, whose laboratory in the Institute for Stem Cell Research (now the MRC Centre for Regenerative Medicine) at the University of Edinburgh, provided a venue for the meeting [8]. A further meeting in September 2011 [9] ratified the aims and objectives of the Group:

- To provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research;
- To encourage and develop all members' interest in research.

The Edinburgh Parkinson's Lectures grew out of the 2011 ERIG action plan when the Group invited Dr Roger Barker, who had given an inspirational talk at the Glasgow Congress, to deliver a public lecture in Edinburgh with the explicit purpose of increasing public awareness in the stem cell and genetic fields. Building joint sponsorship (prompted by Dr Kunath) with the MRC Centre for Regenerative Medicine was made possible when Roger Barker agreed to give a seminar for professional researchers at this center, in addition to the public lecture. The close relationship among patients, carers, members of the public and the research community in regenerative medicine was intrinsic to the new structure.

Such was the success of the Barker lecture, attracting an audience of around 250 (302 applications for tickets, of which 71 were the healthcare professionals), that the group decided to stage a lecture annually, with the aim of increasing public awareness of the condition and of the front-line research being carried out to combat, ameliorate or even cure Parkinson's; the lecture continues to draw ever-larger audiences: Ray Chaudhuri (2013) on nonmotor symptoms, Tony Schapira (2014) on advances in the causes and treatment of Parkinson's, Patrik Brundin (2015) on the end of the beginning in the war against Parkinson's, and Bastiaan Bloem (2016) on the future of Parkinson's care. The link to stem cell researchers has been a continuing one, following the successful model of the initial Barker lecture, as evidenced by Patrik Brundin, one of the world's leading authorities on transplantation techniques, accepting our invitation to give the 2015 Edinburgh Parkinson's Lecture.

ERIG, supported by Dr Kunath and the MRC Centre, continues a regular program of activities, inviting talks by experts from the research community on stem cell research and other aspects of regenerative medicine, as well as topics relating to improving patient care including physiotherapy, exercise and diet. Speakers have included

Professor Dario Alessi, Dr Maria Doitsidu, Dr Ratko Radakovic, Dr Miratul Muquit, Dr Anton Gartner and Dr Alison Green. ERIG supports student projects [10,11], and several members also contribute to research by acting as Lay Grant Reviewers for the grant applications to Parkinson's UK.

The Parkinson's odor project is a direct outcome of branch members' involvement in research. Joy Milne from Perth, whose husband had Parkinson's, met Tilo Kunath at a Parkinson's event and claimed that she could detect Parkinson's in people by a distinctive odor. In collaboration with ERIG, Tilo set up a small research project, using Edinburgh branch members as subjects, to test the claim. Tilo said:

"The first time we tested Joy we recruited six people with Parkinson's and six without. We had them wear a T-shirt for a day then retrieved the T-shirts, bagged them and coded them. Her job was to tell us who had Parkinson's and who didn't. Her accuracy was 11 out of 12. We were quite impressed."

Subsequently, the 12th person was diagnosed with Parkinson's, bringing Joy's accuracy to 100%. The research outcomes were the subject of a BBC news report [12]. As a result, Parkinson's UK has funded a follow-on project involving Manchester, Edinburgh and London Universities, to try to find the molecular signature responsible for the odor and then develop a simple test such as wiping a person's forehead with a swab [13]. This could be a breakthrough biomarker for the condition.

We build our new relationships with our health professionals, educating them in the lived experience of Parkinson's by giving talks and interviews to medical and physiotherapy students and staff at Edinburgh and Queen Margaret Universities; by contributing, with Dr Kunath, to the Cabaret Of Dangerous Ideas at the Edinburgh Fringe; being patients for University of Edinburgh medical students' and applicants to the Royal College of Physicians' diagnostic examinations; participating in training sessions and videos for doctors, and much more. We also had a research poster accepted and displayed at the WPC 2016 [14,21].

The next step toward helping the participative approach take root is knowing how it translates into behaviors and attitudes that support us in maintaining our health and well-being, and that helps us step out of the habitual dependent patient role into a partnership one. How do we overcome the common Parkinson's symptom of apathy which risks keeping us in dependency? Current research [15] indicates that 50% of managing the condition is down to our drug regime, and 50% is our own responsibility, through, in particular, skill-based exercise and mental and emotional attitude. Over the past 20 years, the Edinburgh Branch has developed an enthusiastic membership through monthly Branch meetings with guest speakers addressing Parkinson's issues. We also organize weekly exercise and interest groups for our members, including dance, swimming, pilates, painting, gentle exercise and many more. One off events include weekends on exercise, therapeutic sessions, a full-day seminar on movement and reports by Branch delegates who attended World Parkinson's Congresses of 2010, 2013, 2015 and 2016 (plus 2015 video feeds) disseminating the knowledge gained there. The community is building on this knowledge, especially the effect that diet and skill-based exercise can have on maintaining cognitive as well as physical functioning.

To enter this 'brave new world' of responsibility and active participation, PwP need to develop the mental and emotional skills to take responsibility for their own needs. This is where the Quality of Life Group [22] helps. The group was set up for PwP only, to provide a safe and welcoming environment to share their experiences of living with their condition; what has emerged is a group that has been a catalyst for change in the individual members. With growing trust in the group process members have been able, through time, to share intimate and difficult issues. This has shifted their perception of themselves, normalizing their place in the world, empowering them as individuals and improving their capacity to speak up and get their needs met more often. This in turn strengthens their empowerment – a virtuous cycle (Figure 1).

There are practical benefits to the wider Parkinson community. Quality of Life Group members share their experiences of what works for them, gather more information between meetings and share it, plus hints and tips for easier living, on the Branch website. Feeling more empowered they attend more of the branch activities and take up official roles on committees, giving them more opportunities to pass on their knowledge and experience. They undertake Parkinson's UK training as facilitators to run self-management courses in the area to help and educate other PwP. Research findings indicate, too, that volunteers are healthier and more engaged in society [16] – an important element when apathy and depression can be seriously debilitating cognitive symptoms of Parkinson's. When members take responsibility for their own wellness, they also relieve pressure on their carers.

Guides & partners

In this context, friendship (Box 1) is a powerful word, as is respect, used by Professor Bloem meaning respect for



Figure 1. Quality of Life process.

Box 1. Albert Camus

- Don't walk behind me, I may not lead
- Don't walk in front, I may not follow
- Just walk beside me and be my friend

one another's knowledge. He says: *"The patient is not the expert – the patient and the doctor together are the expert"* and uses the phrase *"the patient as teacher"*. The implication of being guided, of walking with a friend, is that we as PwP need to know where we want the guide to take us, and the guide needs to listen and understand us. In the 'new world', it will no longer be acceptable for PwP to abdicate all responsibility for their healthcare to the professionals.

We suggest that this approach of mutual respect is person-centered, a concept developed by Carl Rogers for treating clients in therapy sessions. In his 1957 paper [17], Rogers put forward the six conditions he deemed 'necessary and sufficient' for psychological change to take place. Three of the conditions apply specifically to therapy sessions; the remaining three, commonly referred to as 'The Core Conditions', are universally applicable to individuals or organizations in promoting growth and well-being:

- Congruence: being real, being genuine
- Unconditional positive regard (UPR): caring, accepting, prizing
- Empathy: understanding.

Applying these three core conditions to the relationships between PwP, their healthcare professionals and their support networks, they become – and in some cases already are – the basis for the reciprocal culture change we are advocating. When Professor Bloem talks about respect he is describing UPR, congruence is evident when he speaks about himself not being the overall expert, and he certainly shows empathy when talking to or about his patients.

Translating these 'core conditions' into how we interact with each other, our health professionals and the regenerative medicine research community gives us a chance to achieve something truly life changing. This requires everyone involved to put aside their old ideas and customs ready to embark on a journey of exploration. As a start, the core conditions can be used to reframe PwP responses:

- *"I feel fine"* replaced with congruence (and candor)
- *"Well, actually, I am feeling great about A, B and C; and I'm worried about X and Y."*
- *"I need more information about possible non-motor symptoms – where do I find it?"*
- *"I need a cure"* replaced with UPR:
 - *"I realize that everyone in research is working their socks off towards finding a cure. How can I contribute? What research projects need participants?"*

Reframing healthcare professional responses and statements:

- “It [the symptom] goes with the territory – not a lot you can do about it” replaced with empathy:
 - “Every PwP is different – this is a ‘Boutique’ condition – and there are things you can do to work with it mentally as well as physically. Here’s a link to the local branch/PD nurse/...”
- “Oh really?” when unusual information given by PwP and/or carer is replaced with UPR and congruence:
 - “That is really interesting – tell me more. . .”

This point is especially relevant to the relationship between the Parkinson's community and the regenerative medicine community. Joy Milne had been telling consultants and researchers about the change in her husband's smell for many years without being listened to.

- “Let's just plod on” replaced by UPR:
 - “Let's see you striding on”

Given the disproportionately strong placebo effect in Parkinson's, words cast spells and must be used with care. As Tirrell says: “Those who seek to change the social order must not ignore the language that embodies it” [18].

Conclusion & a call to action

With a neurodegenerative condition such as Parkinson's, where the restitution narrative is not applicable, “The central problem is how to avoid living a life that is diminished, whether by the disease itself or by others' responses to it” [5,19]. Our aim is to live a life where, in the words of activist and PwP Robin Morgan, each of us can say “I'm not diminished by my Parkinson's, I am distilled by it, and I very much like the [person] I am distilling into” [20]. There are, besides the medicines, “other ways of addressing the experience of living with a disease that help the person ‘reclaim’ [19] their sense of being a person (rather than a patient) for themselves” [6].

First and foremost is the Dalai Lama's concept of wise selfishness: “Being wise selfish means taking a broader view and recognizing that our own long-term individual interest lies in the welfare of everyone” [4]. Wise selfishness gets us involved with others in the Parkinson's community, with research and researchers – not just to do everything we can to help them move toward a cure, although that is always a key aim – but because getting involved keeps us mentally, emotionally, physically and spiritually healthy, and adds immensely to our quality of life, regardless of our physical state. As we move beyond the seduction of an imminent miracle cure and embrace our own responsibility for a life well and positively lived, we also play a key part in supporting regenerative medical research.

Our call to action is fourfold:

- First, catch your researcher! Central to building community and social interest and engagement in research is undoubtedly the involvement of an active and enthusiastic researcher, in our case, Dr Tilo Kunath. We suspect that it is an essential precondition for success by others who hope to foster similar activities to those described in this article.
- Meet, talk and listen. When researchers in regenerative medicine meet – and listen deeply to – the people who will benefit, however tangentially, from their research, the impact is powerful for everyone: “I never knew until now just how important my research is.”
- Make Rogers' three Core Conditions [17] the underpinning of reciprocal respect among PwP, researchers and healthcare professionals. We value facilitated group dialogues to develop these skills.
- Wholeheartedly embrace wise selfishness across the Parkinson's community, and extend the principle into the research community as well.

A final thought

Parkinson's is often referred to as an unwanted visitor that turns up and will not go away. We are, however, finding that the visitor brings gifts. All three authors of this article have Parkinson's: for one author promoting Parkinson's research has become a consuming interest which emphasizes the positive side of having the condition; for another, a way of turning anger at the diagnosis into passion to make a difference; and for another, pride in belonging to and contributing to the whole. In espousing wise selfishness, in walking beside each other, in becoming active participants in our own wellness, we contribute to the research community, to the PD community, and to the wider society. And above all, we find it fun.

Disclaimer

We have written this paper about our activities as members of the Edinburgh Branch of Parkinson's UK. The views we express are entirely our own and not attributable to Parkinson's UK nor to the Edinburgh Branch thereof.

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