

## Advancing treatments and research through partnerships that empower

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

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Members of the Edinburgh Branch of Parkinson's UK are challenging the common cultural perspective that medical care is simply given to patients by doctors. Instead, they have found that promoting events and interactions between researchers, medical professionals and people with Parkinson's disease has led to active partnerships that improve treatment, impact research and empower individuals. Building these new relationships and taking an active approach to one's own wellbeing benefits everyone involved and enriches society as a whole.



### What questions & challenges are raised?

It's not common in today's society to hear the relationship between a doctor and a patient referred to as a partnership or a collaboration. Yet this is exactly the kind of relationship that Ken Bowler and his colleagues from the Edinburgh branch of Parkinson's UK think health professionals, people with Parkinson's disease and the medical community as a whole should aim for. The authors describe how groups such as Edinburgh Research Interest Group (ERIG) and the Quality of Life Group (QLG) have brought people together in new ways, built relationships and have positively impacted treatments, health and research. They emphasise that interactions that have a person-centred perspective and promote mutual respect are essential to establishing these partnerships and meaningful relationships. This involves changing the mind set of health professionals and patients to be more open, receptive, proactive and understanding. Mr Bowler and his colleagues offer insight into the approaches, experiences and people that have made a difference to their wellbeing, the Parkinson community, regenerative medicine research and society at large.

fit from discussions with patients and these can spur new ideas and areas of study. The authors point out that everyone has different motivations to be an active participant in their own wellness and community, but the important overall result is that everyone benefits.

### What insight & direction does this give for research policies?

Ken Bowler and colleagues reference the Dalai Lama in their writing to bring up a very important point, that we should all strive to help our communities and societies because we benefit when the welfare of everyone improves. The authors emphasise that individuals should try to build relationships and have open discussions that embrace mutual respect. These relationships greatly improve the work and lives of everyone. Medical professionals who form partnerships with individuals with Parkinson's (or other neurodegenerative conditions) are better able to meet their needs and learn more about the day-to-day experience of Parkinson's. Conversely, people with Parkinson's can greatly improve their wellbeing by openly discussing their needs and experiences. Expanding this to support groups, an individual's community and even researchers can help individuals build relationships and engage with society. Active participation or volunteering in one's community has been shown to counter apathy and depression, common symptoms associated with Parkinson's. The authors also point out that half of managing a medical condition lies in how an individual takes responsibility for their own wellbeing. This is greatly helped by individuals actively educating themselves and seeking out researchers to talk with and listen to. Researchers bene-

### What background and point are discussed?

Mr Bowler and his associates state early on in their commentary that becoming an active participant in one's own wellness has many benefits but is not a straightforward journey. Learning to effectively communicate, building relationships, educating one's self, taking on personal responsibility and getting involved with one's community all help facilitate changing a person's outlook from a passive recipient into an active participant. The authors point out that education plays an important role in enabling individuals with Parkinson's disease to understand how the disease affects them, what medical research recommends, and how to manage symptoms and take care of themselves. The Edinburgh branch of Parkinson's UK created the ERIG as a community of patients, researchers and medical professionals interested in learning about, sharing and discussing current Parkinson research. The group has grown to hold a regular program of events and lectures by renowned stem cell and regenerative medicine researchers. Members are also involved in reviewing grant applications as Lay Grant Reviewers and have prompted new avenues of research, such as the Parkinson's odour project. Another important group for Edinburgh's community of people with Parkinson's is the QLG. Mr Bowler and colleagues state that this group aims to provide a safe environment where people with Parkinson's can discuss living with the condition. These discussions allow individuals to normalise their perception of themselves within the community, become empowered, and then share their experiences with others. This cycle of communication, perception and empowerment greatly helps improve an individuals' quality of life by encouraging them to openly discuss their needs. Key to both of these groups' success has been the active effort of individuals to build relationships and trust by sharing information and life experiences. The authors specifically highlight the importance of how individuals communicate, particularly for building patient-doctor partnerships. The authors give several examples of how discussions between people with Parkinson's, medical professionals and researchers can be turned into more meaningful and informative discussions by being genuine, believing in each other and doing his or her best to empathise.