



Quality of Life Group: Background

A PD diagnosis can be a devastating experience, with emotional trauma (we don't use the word lightly) in the moment. Few people in that first meeting can calmly discuss the diagnosis' implications with their physician, so in the following days and weeks they format their own prognosis, usually negatively.

In this all too familiar scenario the person with Parkinsons (PWP) is left knowing they have an incurable neurodegenerative disease. :

- Where do they go from there?
- What is their place in the world?
- Who should they tell, if anyone?

These, and 101 other questions, can be debilitating. While there is medical help, there is little emotional support, so how do PWPs maintain their mental, physical, emotional and spiritual wellbeing?

This has led us to believe:

The medical model is necessary but not sufficient.

So in April 2015 we set up the first Quality of Life Group in Edinburgh, Scotland. Here are the philosophy, principles and structure we use to run a successful group; and the outcomes and benefits we gain from it. We hope this will give you the help – and courage – to start your own group.

QL Philosophy

- **We focus on our emotional and spiritual needs**

This is about how we deal emotionally with what the world throws at us now that we have PD. We learn how to maintain our sense of humour and our fighting spirit.

- **We reframe our future story**

We have been told all too often that after diagnosis: "You have five good years left." RUBBISH! There are people in our QL group 20 years on, mobile and with a wicked sense of humour. There are 'mountains to climb', relationships to be cherished and a whole world out there to be conquered!

- **We restore our choices:**

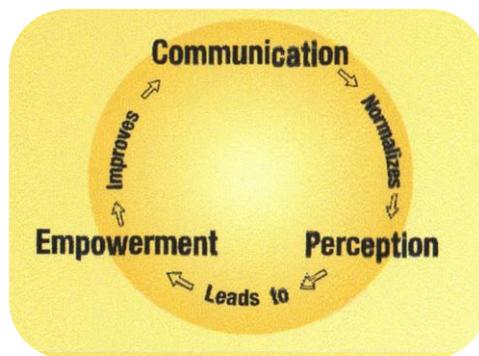
- Sharing experiences of the absurdities of PD we learn to laugh at them
- Sharing hope we support others and strengthen ourselves
- Sharing practical ideas we improve our day-to-day lives

QL Outcomes & Benefits

Working with this philosophy our perception of ourselves and our place in the world has changed: we speak up and are heard, so our needs are met more often.

Mutual support and understanding empowers us to

- Communicate openly and congruently
- Take personal responsibility for our mental, emotional and spiritual health
- Maintain our physical health in partnership with our health professionals
- Accept we are individuals in society, not defined by our Parkinson's
- Listen to ourselves and trust our inner voice
- Know what our needs are, and tell the world clearly



**We gain more self confidence, which empowers us to speak up,
and so we go on, and on, creating a virtuous circle**

Themes that arise in meetings

- What keeps us laughing
- Challenging apathy
- Improving communication with loved ones, care partners, families
- The embarrassment of farting, and worse, in public

Members say:

"It is wonderful being in a group where you don't have to explain or apologise!"

"... a joyous gathering, sharing our experiences and building trust in such a healing atmosphere."

"The feeling of understanding and companionship was heart-warming. My quality of life has already gone up!"

"It is great to talk about PD without fear of boring or worrying anyone!"