



Quality of Life Group

Maintaining our mental, physical, emotional and spiritual wellbeing

The issue

A Parkinson's diagnosis can be devastating and emotionally traumatic. Few people can discuss it calmly there and then: all they know is they have an incurable neurodegenerative disease.

They are subsequently left with 101 questions ranging from: Will I die? To: Who will I tell, and how?

As the condition progresses a whole new range of issues emerge including mobility, speech, dexterity....

While medical help is usually readily available there is little to support people's mental, emotional and spiritual needs.

Medical intervention is necessary but is not the whole story



"The central problem is how to avoid living a life that is diminished, whether by the disease itself or by others' responses to it" (Houston 2015:31).

Forming a QL Group

To enable everyone to share their thoughts and feelings you must ensure a safe and friendly environment, follow our suggestions below.

Agreements

- Members: PWP's ONLY
- Confidentiality: Outside the meeting we can share what was said, but not who said it
- Respect: Everyone's contribution matters – we listen without interrupting

Space

- Must be private
- Comfortable
- Wheelchair access
- Circle of chairs
- Refreshments

Simple Process

The QL group meets monthly for an hour and a half.

- Self-managed – no 'leader'
- Opening script to remind us of the agreements
- Checkout
- Consistent date and timing (eg First Thursday of the month for an hour and a half)

Themes, Ideas for Meetings

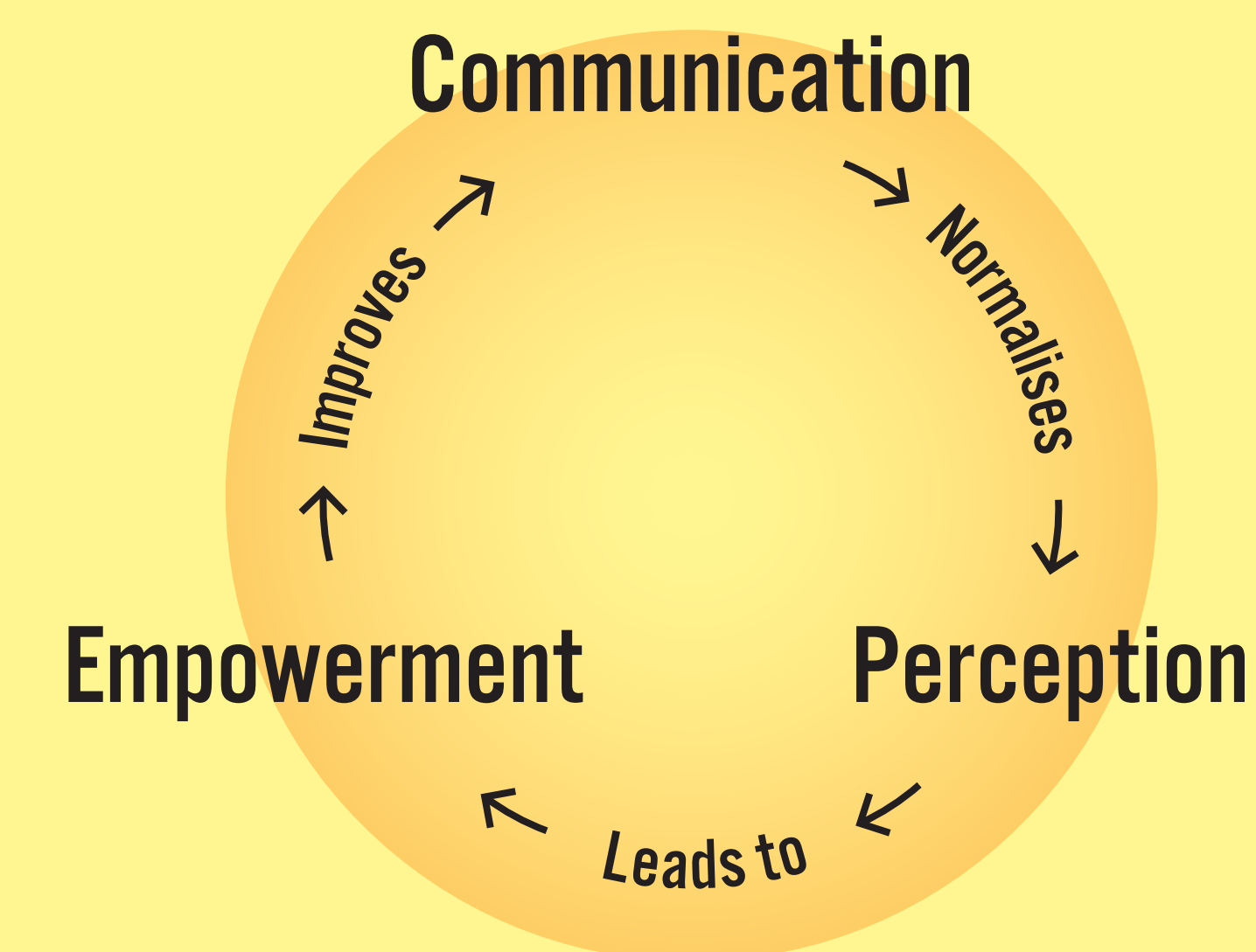
- What keeps us laughing
- Challenging apathy
- Improving communication with loved ones, care partners, families
- The embarrassment of farting, and worse, in public

QL Philosophy

- Focuses on our emotional and spiritual needs
- Helps us reframe our future stories
- Restores our choices by:
 - 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 living

Outcomes

Our perception of ourselves and our place in the world changes: we speak up and are heard. Our needs are met more often.



This gives us more self confidence, which empowers us to speak up – and so we go on, and on – creating a virtuous cycle.

QL Benefits

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

"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!"

"The special time, place and positivity of the QL group."

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