

"Your PD is your own. A crystal ball is not helpful – live now" (Tom Isaacs)

JANE BUSCH – FRAMEWORK FOR SELF-CARE: 5 Keys

Nutrition:

8 glasses of water a day, plus everything in the nutrition seminar.

Supplements:

Vitamin D, Calcium 1200 mg per day; a good multivitamin.

Exercise:

Motor movement and physical activity boost the immune system, lift mood and enhance cognitive reserve. Exercise for aerobic, cognitive challenge, flexibility and balance, strength and resistance (using weights and resistance bands).

Mindfulness:

Paying attention non-judgementally, moment to moment, appreciate others. We cannot change the past – *put it on the raft and let it float off down the river*. Who knows what the future will bring.

Volunteering:

Gives a sense of purpose. Volunteers are happier. It builds strong relationships.

The rewards are felt in the heart and stored in the soul....

BOB KUHN – ATTITUDE

The one thing we have complete control over is our attitude. Attitude is your best choice:

we have real lives to live, with adventure and purpose in pressing on, in persevering.

(Blog: Positively Parkinson's)

Challenge with three words:

ENGAGE

ENCOURAGE

INSPIRE

PD has attempted to control my life (depression, loss of identity, taken over every aspect of living; feeling invaded, frightened, stressed, embarrassed).

Choosing a positive attitude gives:

- 1) Strength and hope to others: friends and family. When we model courage and resilience, leave the legacy – an inheritance of hope.
- 2) Strength and hope to ourselves – renewed sense of confidence.
- 3) Physically, mentally and emotionally – it becomes a *virtuous* cycle.
- 4) Only logical way to play the cards we are dealt.

How do we ground the choice of attitude?

- Hope at its best is recognising the worst and still hoping for the best. Sparking creativity
- How do we acquire and replenish hope?
 - Have a purpose, and reason. Not passive hope.
 - Passionate purpose – choose a challenge – inner strength – getting up again – learn from failure.

Go beyond our needs and wants:

- ENGAGE
- ENCOURAGE – put heart into
- INSPIRE – breathe life into

DILYS PARKER – COMMUNICATION

The words we use define us and our world – they can empower or disempower.

Stories are therapeutic and healing; they are helpful to others, giving richness and depth. Untold aspects emerge – alternative narratives reframe how we think about ourselves and our condition. They help us to deal with society's narratives, for example of 'normal.'

Stories become even more important as the non-verbal signals are missing or radically changed.

"Life is changed in the instant, the ordinary instant" (*Joan Didion* "The year of magical thinking")

- 1) Hearing the news
- 2) Sharing the news
- 3) Narrative ideas

Language can separate us from the problem. We can objectify the uninvited guest, and locate the problem outside of me; no self-blame. **The person is not the problem – the problem is the problem.**

Hearing the news: the power dynamics of relationship – inherent power imbalance between PWP and the physician: paternalism.

What we want from the physician: a second appointment to bring questions; PD (PUK) nurse – how I was made to feel. Building confidence and trust by listening, taking time and care in an unhurried way, active involvement. Active listening and shared understanding.