

Creating a virtuous cycle of PwP support

The journey: From impairment to empowerment

How do newly-diagnosed people with Parkinson's (PwP) make the journey from shocked and petrified patients to confident, engaged and empowered people, working in partnership with health professionals and support services, taking responsibility for their own well-being?

What we did

Members of the Edinburgh Parkinson's Branch generated ideas for reaching a wider number of PwP locally. We analysed these ideas, grouping and clustering them in categories.

What we found

We found an emerging pattern of why newly diagnosed PwP stayed with the Branch. As they took their first tentative steps towards finding out about Parkinson's, very often through attending one of the monthly Parkinson's cafes, or joining the Dance for Parkinson's class, they found empathy, information and encouragement from more established members. Peer to peer – PwP to PwP – support for new and newly-diagnosed members helped them to take part in the Branch's many activities and classes.

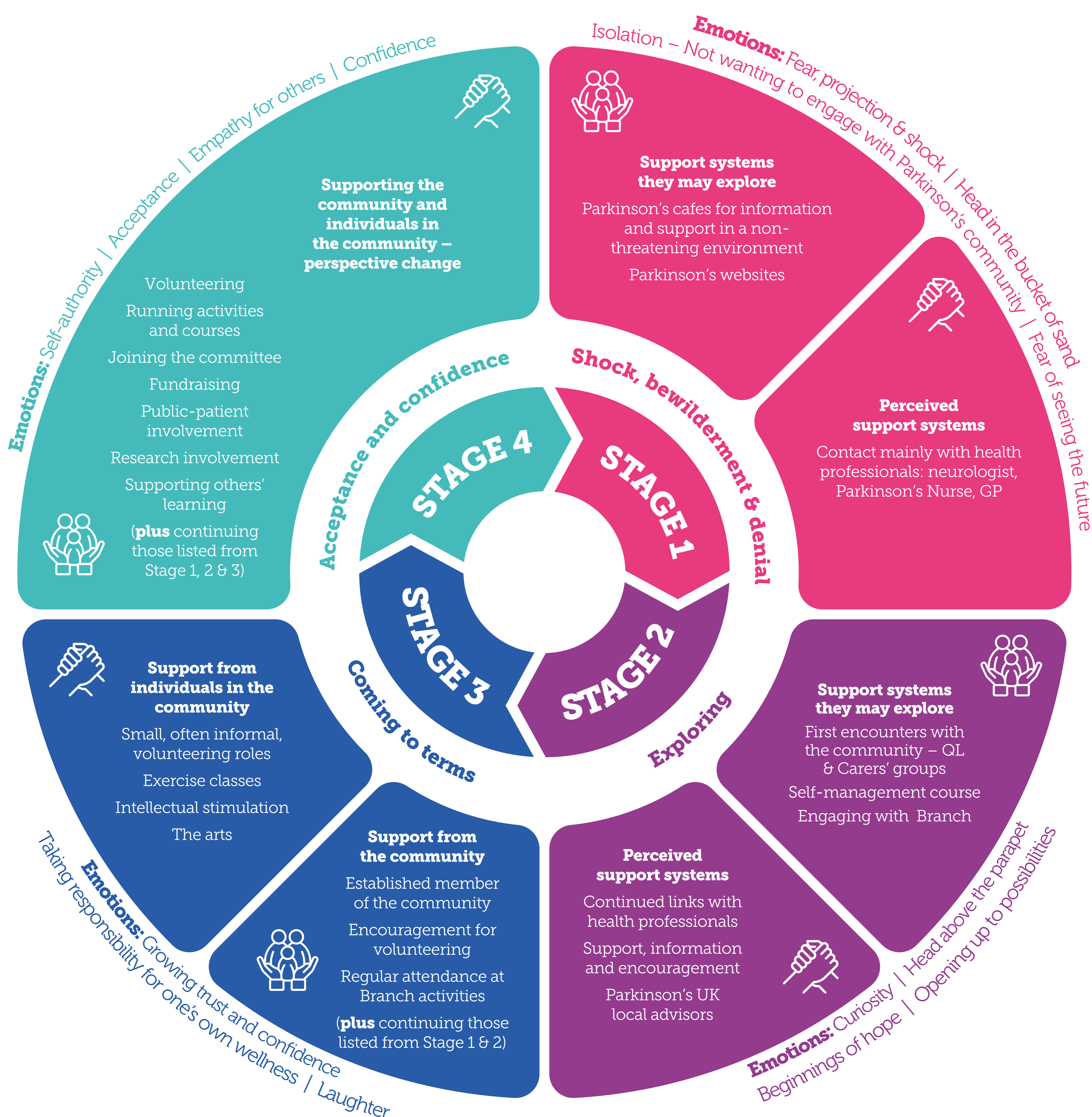
We observed that as new PwP and their partners gained in confidence through joining in, as well as joining, the community, they eventually became a resource and support for other members, in the same way they themselves had been supported.

What emerged

There are, we found, four stages to this journey:

- Stage 1: dismay and an inward focus – what will happen to me? – and an absolute dependence on their health professional's opinions
- Stage 2: first tentative meetings with other PwP and the local community, joining in activities and learning about the condition from others' lived experience
- Stage 3: 'coming into themselves' and taking responsibility for their own wellness
- Stage 4: when the focus moves beyond self, to contributing to the community

These empowered PwP support the newly diagnosed, repaying the debt they owe to the PwP who supported them in the first stages of their own journey and growth: creating the virtuous cycle of support.



Relationship with health professionals

From total reliance to partnership

The learning

From ignorance to knowledge

The emotional responses

From negative to positive

Self-help

From passivity and apathy to activity and oomph

Opening up and openness

From isolation to community