

Dancing with Parkinson's: a London hospice's experience of running a dance programme

Margaret Clifford, Simon Robey, John Dixon

Parkinson's Disease (PD) is a neurodegenerative condition caused by the loss of dopamine-producing cells from the substantia nigra in the mid-brain. It causes tremor, rigidity and bradykinesia, as well as a number of other motor and non-motor manifestations (National Institute for Health and Care Excellence (NICE), 2017). The prevalence of PD in the UK in 2009 was 127 000 cases (27.4/ 10 000 population) and is estimated to increase to 161 000 by 2020 (Parkinson's Disease Society, 2009). The worldwide incidence of PD is estimated at between 8 and 18.6 new cases per 100 000 population per year (de Lau and Breteler, 2006). Although a number of treatments are available to control symptoms (e.g. levodopa, dopamine agonists), PD is a progressive incurable illness. As such, palliative care provision is considered a core part of its management and is included in the NICE *Guidance for Parkinson's Disease in Adults* (2017).

At the heart of palliative care is the idea of enabling every individual with a progressive incurable illness to live as well and as actively as possible until they die. To this end, St Joseph's Hospice in East London runs a number of group support programmes, including a group for people with neurodegenerative conditions. A member of this group with PD suggested developing a 'Dancing with Parkinson's' programme, having had a positive experience with a dance class elsewhere.

There is a growing body of evidence to support the benefit of dance in people with PD (McNeely et al, 2015; Shanahan et al, 2015). Many different dance techniques have been studied, e.g. the Argentine tango, ballroom, Zumba Gold and Irish set dancing. The nature of benefits varies across studies/programmes, but includes improvement in motor function, balance and fatigue as well as overall enjoyment and activity participation (Foster et al, 2013; Romenets et al, 2015; Delextrat et al, 2016; Shanahan et al, 2017).

After securing some external funding, the hospice set up a pilot dance programme for people

with PD comprising six fortnightly 1.5-hour dance classes over 12 weeks.

Developing the dance programme

The hospice connected with specialist dance artist, Danielle Teale, who is a highly experienced 'Dance for Parkinson's' practitioner. Teale and the hospice worked together to establish the classes in partnership. The class was advertised widely across East London, including in local newspapers, via local PD specialist services and within the hospice. Anyone with a diagnosis of PD who was able to travel to the hospice for the classes was considered eligible to attend, regardless of disease stage or mobility.

During the dance classes, participants engaged in both lyrical and rhythmic exercises in time to live music, alternating between standing or seated exercises with combinations of hand and arm or full body movements. Those who were unable to stand were invited to participate in movements in a sitting position. Classes incorporated lead and follow exercises focusing on motor skills, as well as improvisation and creative dance tasks enabling contribution from the participants.

Evaluation

The following outcome measures were used:

- Parkinson's Disease Questionnaire (PDQ-39): a validated quality of life measure for Parkinson's disease containing 39 questions covering 8 dimensions; mobility, activities of daily living, stigma, social support, cognition, communication and bodily discomfort (Peto et al, 1998; Jenkinson et al, 2014). Summary scores for each domain and an overall summary index (PDQ-39SI) were calculated (higher score denotes worse quality of life)
- Goal Attainment Scaling (GAS): a technique that captures the extent to which an individual's pre-identified goals from an intervention are achieved. Goals are rated before the intervention according to importance and difficulty, and afterwards

Margaret Clifford
Clinical Lead Consultant
in Palliative Medicine, St
Joseph's Hospice,
London

Simon Robey
Complementary
Therapies and Namaste
Care Coordinator, St
Joseph's Hospice,
London

John Dixon
Lead Acupuncturist, St
Joseph's Hospice, Mare
Street, London

Corresponding author:
M.Clifford@STJH.org.uk