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Title page:

Main title: Exercise for people with Parkinson's: A practical approach

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Exercise for people with Parkinson's: A practical approach

Abstract

Exercise is key to attaining a healthy and productive life. Furthermore, for people with Parkinson's, exercise has reported benefits for controlling motor and non-motor symptoms alongside the use of pharmacological intervention. For example, exercise prolongs independent mobility and improves sleep, mood, memory and quality of life, all further enhanced through socialisation and multi-disciplinary team support. Recent research suggests that optimally prescribed exercise programmes following diagnosis, may alter neurophysiological processes, possibly slowing symptom progression.

Given the benefits of exercise for people with Parkinson's, it is vital that professionals encourage and motivate individuals to exercise regularly from the point of diagnosis, and provide guidance on what exercise they could be doing. The timing of provision of information about exercise will depend on the role of the reader as part of a multi-disciplinary team, and the approach the team members take in communicating the importance of exercise in addition to other relevant aspects to the management of Parkinson's.

This feature provides examples of how the growing body of evidence on exercise for people with Parkinson's is revolutionising the services they are provided. It also highlights new resources available to help the wider support network (people such as volunteers, spouses and friends of people with Parkinson's) with an interest in exercise promote a consistent message on the benefits of exercise.

Introduction

World Health Organization (WHO) recommends at least 150 minutes of moderate-intensity, aerobic physical activity (PA) a week¹. I.e. Someone doing exercise should have a raised heart and breathing rate, feel warmer, and find talking hard. However, people with Parkinson's can be 30% less active than age matched peers^{2,3}, with some reported as inactive 70% of the day⁴. Hence, Parkinson's-specific guidelines endorse early referral to appropriate professionals for an informed discussion about the impact of PA and exercise on their lifestyle^{5,6}.

People with Parkinson's, who exercise regularly, emphasise that it enables them to stay active and contributes to a sociable, healthy lifestyle. They also highlight that it provides a means of taking control and fighting back against their condition⁷. For those who push exercise to an intensity beyond their previous level, and when still realistically capable of recapturing a prior physical ability, it can mean taking on challenges they had hitherto believed impossible (See Box 1). For most people however, the practicality of exercise is in the maintenance of baseline health and fitness levels to stay mobile for as long as possible.

Box 1. Jane's thoughts about exercise

Exercise has radically improved my life with Parkinson's. Regular, and increasingly intensive exercise has had a significant effect on my symptoms.

Exercise has reduced my adverse motor symptoms. In some ways, more significantly, it has kept me positive emotionally. I feel good about my body again. I believe I am doing something to control my condition. 10 years after diagnosis I can confidently abseil down a waterfall and hike up 3000 feet below Mont Blanc!

I have only needed a small increase in my Madopar dose over the 5 years I have been exercising.

My only regret is that I wish I had started exercising to this level immediately after diagnosis.

Exercise alone cannot sufficiently treat the symptoms of Parkinson's for the majority of people and is recommended as one part of the whole approach adopted by a multidisciplinary team. Different team members should utilise their knowledge to communicate and discuss choices of pharmacological and non-pharmacological interventions e.g. diet, exercise, social prescription, for a balanced management and optimal outcomes.

The evidence around exercise

Compelling evidence supports the importance and value of exercise for people with Parkinson's⁸. There are two main aims of exercise for people with Parkinson's, which are preserving function (which will vary over the course of Parkinson's) and modifying disease progression. Different forms of exercise may be beneficial for these aims. Research demonstrates improvements in:

- **motor symptoms** using varied exercise styles (Figure 1) that generate strength and power through resistance training. These gains are associated with better balance, gait parameters, functional ability and quality of life^{6,8-11}. Further improvement is reported where early rehabilitation combines co-ordination of limb and trunk movements (with or without additional complexity) and increasingly challenging cognitive ability, through dual and multiple tasking exercise routines¹²

[Please insert Figure 1 near here, and title it: **Figure 1: Types, dose and examples of ideal exercise for People with Parkinson's**]

- **non-motor symptoms** associated with improved sleep, fatigue and mood and with a reduction in constipation, depression, anxiety and apathy^{6,8-11}
- **cognition**. Several authors have reported a connection between exercise participation, enhanced memory and associated executive functions^{7,8-14}. They noted a positive impact on cognitive abilities, including rational thinking (planning and organising) reading, learning, and memory^{15,16}
- **secondary complications**, such as reducing discomfort from musculoskeletal and central pain, and other medical conditions affecting general health and mobility⁶

- **disease progression**, with animal model and clinical studies suggesting a potential neuroprotective role of exercise¹⁷. In particular, higher-intensity activity (increasing to 80% maximal heart rate), which may be mediated by changes to cerebral blood flow, enhanced turnover of neurotrophins (such as brain-derived or glial-derived factors, BDNF and GDNF) neurotransmitter modulation, and improved cortical plasticity¹⁷⁻²¹

Functionally, exercise can help with recalibration of bradykinetic (slow) and hypokinetic (small) movement using complex and large, amplitude-focused exercise^{9,11,13,20}. This translates into an improved ability for people with Parkinson's to plan, think, recall facts and learn, all of which have a positive impact on falling (one of the most feared consequences of Parkinson's and a key barrier to exercise participation).

Barriers to, and decisions on when not to exercise

People with Parkinson's experience both personal and environmental barriers affecting engagement and ongoing participation in exercise^{6,24}.

Frequently reported barriers include:

- Low expectations of what exercise can help with
- Lack of perceived benefits of exercise
- Insufficient time or motivation to exercise
- Costs and transport or accessibility of classes
- Fear of falling and safety considerations (where multi-pathology exist).
- The lack of available activities to suit personal choice

Other factors affecting participation include bad weather, prior experience of exercise, gender, and age (with older women generally less likely to take up exercise).

However, both a recent study investigating how people who receive exercise support reconceptualise their physical and cognitive resources²⁵, plus increasing enquiries from people with Parkinson's about access to specialist services and education, highlight a clear shift towards individuals actively wishing to participate in exercise as a means of taking control of their condition.

Whilst no exercise done correctly has been demonstrated as harmful in research trials, there may be times when the role of the specialist nurse or consultant is to monitor their patient's behaviour. For example, the introduction of a new programme of exercise may give rise to unrealistic expectations of people with Parkinson's or their carers, or medication might create impulsive and excessive responses to the undertaking of exercise. As the condition progresses, and people develop a greater falls and injury risk e.g. from freezing episodes, postural instability, or to the effects of 'off' periods as medication is wearing off, extra precautions must be discussed for the person's safety.

Comorbidity may add to pain or fatigue levels, both of which may be felt more acutely if the patient is 'off', or the person may be on medications such as beta-blockers, affecting their ability to raise their heart rate response sufficiently to match exercise demands⁶.

On the whole, exercise should be suggested as undertaken when the body's response to medication is optimal e.g. in the first couple of hours post dose, to gain improvements offered through exercise.

In summary, the benefits of participating in exercise, in terms of current symptom management and the potential impact on Parkinson's progression, highlights the need for clear and effective guidance in order to improve physical activity in this group of people.

The role of each multi-disciplinary team member differs in how they should support factors that enable individuals to exercise and set realistic goals that identify and reduce barriers. For some, such as neurologists, geriatricians and specialist nurses, their responsibility is in knowing who has expertise in exercise delivery, and to refer the person with Parkinson's onwards to the correct service⁶.

The Parkinson's Exercise Framework

The Parkinson's Exercise Framework is part of the eHealth drive, providing a web-based (some information as downloadable) resource to communicate the benefits of exercise to people with Parkinson's.

The Exercise Framework (Figure 2) was developed by a team of experts in their field (underpinned by clinical experience and international evidence) to help answer the question, 'What exercise is best?' This model encourages people to engage in exercise and make it part of their daily routine. It also supports decisions about which exercise method or style might be beneficial at different times during the course of Parkinson's. The examples provided in the Exercise Framework are not exhaustive.

[Please insert Figure 2 near here]

The Exercise Framework is principally targeted towards professionals prescribing physical activity, but openly accessible to people with Parkinson's and their families. Clinicians who are part of the multi-disciplinary intervention and who deal with the diagnosis and ongoing review of people with Parkinson's e.g. neurologists, geriatricians and nurse specialists, should be aware of this online information, and recommend individuals explore the resource. It is supported by literature reviews, research evidence and lived experience of people with Parkinson's, and presented as video cases, animations and suggested exercise types and doses.

Exercise can be done alone or in company. However, exercising in company increases the positive qualities of socialisation, such as competition and the support of family or peers with or without Parkinson's²⁵. Parkinson's UK are making available information about local providers so medical colleagues and specialist nurses to refer individuals to appropriate services. Where people prefer, or have to exercise unsupervised, technology can assist in the creation of a routine. The Exercise Framework suggests the use of Home-based DVDs, or exergaming, e.g. Nintendo Wii or X-Box Kinect.

Box 2. What a neurologist might consider about exercise during a clinic appointment²⁶: An example of how CC approaches the issue during a consultation

1. Check the exercise history from every patient – what they do, how often and how intense? Use the information to understand if it is at sufficient to get out-of-breath and sweaty? Are they meeting WHO guidelines? Is it vigorous enough where appropriate?
2. Re-enforce the positives – keep gardening, doing the housework, walking the dog, looking after the grandchildren – anything that is associated with increased activity; encourage return to activities they may previously have enjoyed – tennis, cycling, golf.
3. If not exercising sufficiently, explore barriers – pain, co-morbidities, confidence, transport difficulties, mobility problems, motivation
4. Also explore solutions. This may be a referral to a physiotherapist for targeted advice and confidence building – exercise ‘buddy’; different modalities – static bike, walking, swimming, chair-based groups; talk through specifics (e.g. In your 30 minute walk, ensure that you are walking sufficiently briskly to get out of breath for at least 10 minutes of it; try going for 2 walks a day, rather than one; try and pick a route that has a hill, so that you do get out of breath; aim for at least 5000 steps per day); set personalised individual goals (e.g. Walk in your garden with your frame for 5 minutes twice a day, and then gradually build it up to 10 minutes twice a day, and then 15 minutes; try doing a sit- stand on your own from your chair, and then every day try and do one more than the day before)
5. Stress the need for sustainability – it has to be something they enjoy so they are motivated to continue it; explore the added benefits – social interaction, meeting a personal goal; engage the partner or other friend or family member.
6. Direct them to the Parkinson’s UK exercise website, the animations and videos [see Resource section]; enclose the exercise leaflets and the list of trained providers in the clinic letter; explain current thinking about the benefits of exercise.
7. Ask about exercise again at next review, and ensure the PDNS continue to re-enforce the message between clinic visits

Please note, that where a consultant perceives lack of time and limited training as personal barriers to discussing exercise with patients, they should identify supporting partners within their communities to ensure exercise is explored and followed up^{26, 27}.

Models from a northern and southern city in the UK and how they inform practice

Box 3. The Sheffield model

Development: Like many of the classes run throughout the UK for Local Groups of Parkinson’s UK, the Sheffield exercise classes were developed by physiotherapists to enable people in the community to maintain, or improve, mobility and physical independence after periods of hospitalisation. The classes promote a long-term supportive and educational environment for participants to exercise and socialise with like-minded people. They are open to the estimated 1,000 people in and around Sheffield with Parkinson’s, run independently of intermittent local health service courses.

Links and partnerships: Links with Sheffield Hallam University provide opportunities for health (including medical) and sports science students to observe classes. Some have since volunteered assistance, and others researched aspects of a class, providing evidence for funding bids, as tutor fees, room rental and equipment are managed through funds raised by Sheffield Local Group members, donations or grant applications. In return, class participants volunteer their time as models for medical students examination and 'Patients as educators'.

The role of consultants and specialist nurses: The support of consultants in adding their names as referees to grant applications has enabled the expansion in class types available to members, and led to partnership provision with the leisure and private sectors. In addition to supporting funding opportunities for exercise classes, the consultants and specialist nurses now refer newly diagnosed patients to the classes run by the Local Group. The classes are co-ordinated by a volunteer physiotherapist (BR) and led by tutors with differing skillsets at facilities across Sheffield, and venues chosen to enable people across the city to access them through assorted transport. For example, at Leisure and Sports Centres, which host the circuit (Figure 3) and boxing training sessions; a dance studio for the seated dance to music, a church hall for the voice class, and Conductive Education classes; a GP practice and private physiotherapy clinic in different areas of the city for posture classes (Figure 4); aquarobics and hydrotherapy in a local heated pool (Figure 5); monthly walks in four local parks (Figure 6) and privately run PD Warrior classes held at the grounds of Sheffield United, one of the city's local football clubs.

[Please insert Figures 3- 6 near here which are photos from classes (permission obtained from participants for publication use). Figure 3. Circuit class; Figure 4. Posture and balance; Figure 5 Aquarobics; Figure 6 Green gym before monthly walk in local park)

Details of the Sheffield Local Group's activities and classes can be found at: <http://www.parkinsons.org.uk/sheffield>.

Box 4. The Plymouth model

Development: A 2016 evaluation of Parkinson's UK local groups, based in Devon and Cornwall, revealed that 72% provided exercise classes. Almost all identified barriers to providing frequent classes (more than monthly). These were transport, volunteer capacity, funding, participant motivation and instructor availability. To address these, whilst increasing exercise opportunities for people with Parkinson's, a pilot scheme was developed in Plymouth, funded by Active Devon, and with support from Parkinson's UK. The scheme delivered Parkinson's-specific training to community exercise providers. This helped to provide a range of local community-based exercise to people with Parkinson's, encompassing a range of activities that they may find enjoyable.

The 3-hour pilot course, with clear aims and learning outcomes (Table 1), took place in November 2017. The 25 delegates provide a range of exercise types including dance, spinning, football and circuits. Their initial feedback demonstrated an increased self-

perceived knowledge of Parkinson's, its management and challenges, as well as increased confidence in suggesting exercise to people with the condition. For example, people stated in their feedback:

- I feel empowered
- I enjoyed the course. I began today with no knowledge and now leaving with extensive knowledge. How to help and the importance of exercise.
- Worthwhile and valuable, providing information about PD activity and the rationale behind why certain things are important in exercising
- • Very worthwhile. Great to hear from health professionals and increase understanding
- of 'why'. Much clearer now as to how I can work with people with Parkinson's

Links and partnerships: The hope is to increase numbers of trained providers within the region with support from Active Devon and community exercise providers (health clubs and gyms). A course will be made available, with supporting documentation, as an 'Exercise Provider Training Toolkit' via the UK Parkinson's Excellence Network.

The Parkinson's-trained, community exercise providers' details are accessible to local groups, with opportunities for participants to feedback their experience of classes.

The role of consultants and specialist nurses: Newly diagnosed patients in the Plymouth nurse-led pathway are now routinely assessed for attitude to exercise, provided with resources relating to exercise provision and the list of Parkinson's trained providers, and directed towards a video of a patient's experience of the benefits of exercise.

<https://www.youtube.com/watch?v=H997qAkIWFM&feature=youtu.be>

The resources, alongside advice about the minimum level of moderate intensity exercise, are provided with clinic documentation, and emphasised during follow-up appointments to patients attending the specialist Parkinson's neurology service in Plymouth.

Conclusion

Clinicians must address communication inconsistencies about exercise and sedentary behaviour to people with Parkinson's. Messages about 'daily prescribed' exercise should start from diagnosis, and be delivered with the support of the multi-disciplinary team, to compliment decision in the use of pharmacological intervention in a variety of ways that resonate with the individual. Referrals to classes should be supported by health professionals or informed community exercise providers.

Parkinson's is for life, and the challenges faced by individuals relate to the complexity and changes in motor and non-motor symptoms, so a one-size-fits-all exercise approach won't work. A 'what', 'when' and 'how to' exercise framework addresses these issues, encouraging individuals to exercise regularly, correctly and preferably with others.

Motivation, ability and circumstances vary in people with Parkinson's, so it is essential to convey the significance of the wide-reaching benefits of exercise in controlling some of their symptoms. Regular and targeted exercise can help people with Parkinson's stay well, regain self-restricted mobility, make them more resilient to stress, and help them to remain active and independent for longer.

The role of medical professionals therefore is to support a sustained motivation to exercise, whether providing by referral onwards (to seek web-based information or local classes), or through advice about exercise benefits, and encouragement during clinic appointments.

Resources

1. The Parkinson's Exercise Framework:

Please share the Parkinson's Exercise Framework with your networks. Available to read and download at <https://www.parkinsons.org.uk/professionals/exercise-framework-professionals>

2. Comprehensive patient-facing pages on exercise:

- Through Parkinson's UK at: <https://www.parkinsons.org.uk/information-and-support/exercise>
- Through the Parkinson's Foundation, including a tab to research evidence on exercise. 'Better lives together: exercise research' page available at <http://parkinson.org/Understanding-Parkinsons/Treatment/Exercise>

3. A podcast featuring discussion between two UK medical schools and schools of health describing their curriculum approaches for the current students to upskill them to deal with the physical activity issue for tomorrow's patients at:

https://soundcloud.com/bmjpodcasts/physical-activity-in-the-curriculum-impact-in-schools-of-medicine-and-new-healthcare-professionals?in=bmjpodcasts/sets/bjism-1&utm_source=soundcloud&utm_campaign=share&utm_medium=twitter

4. The Exercise is medicine resources at:

https://www.exerciseismedicine.org/support_page.php/healthcare-providers/

- For health and fitness professionals: https://exerciseismedicine.org/assets/page_documents/ExPro_Action_Guide.pdf
- For physicians prescribing and referring for exercise: <http://www.exerciseismedicine.org/physicians.htm>
- A healthcare action guide: http://www.exerciseismedicine.org/assets/page_documents/Complete%20HCP%20Action%20Guide.pdf

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Key points:

1. For people with Parkinson's, varied exercise is increasingly evidenced as beneficial for controlling the challenges of their motor and non-motor symptoms.
2. Whilst there is no 'one size fits all' model, a web-based framework of suggested exercise exists.
3. Health professionals must take responsibility for getting out a clear message highlighting the benefits of early, targeted and regular exercise to improve physical health and wellness in this population group.

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Table1: Pilot course aims and learning outcomes

| |
|--|
| <p>Aims of the course</p> <ul style="list-style-type: none">▪ Increase knowledge and understanding of Parkinson's▪ Identify the needs of people with Parkinson's and the benefits of challenging, higher intensity (vigorous), high frequency exercise with cognitive load.▪ Give people the ability to identify the challenges associated with the symptoms of Parkinson's and strategies to help▪ Explain when vigorous exercise is needed and how gentle exercise is also very beneficial |
| <p>Learning outcomes</p> <p>After taking part in the course delegates will be able to:</p> <ul style="list-style-type: none">• Understand the key challenges of living with Parkinson's• Identify the importance of regular, vigorous exercise in keeping someone with Parkinson's active• Evaluate their own practice in providing the correct activities for people with Parkinson's |

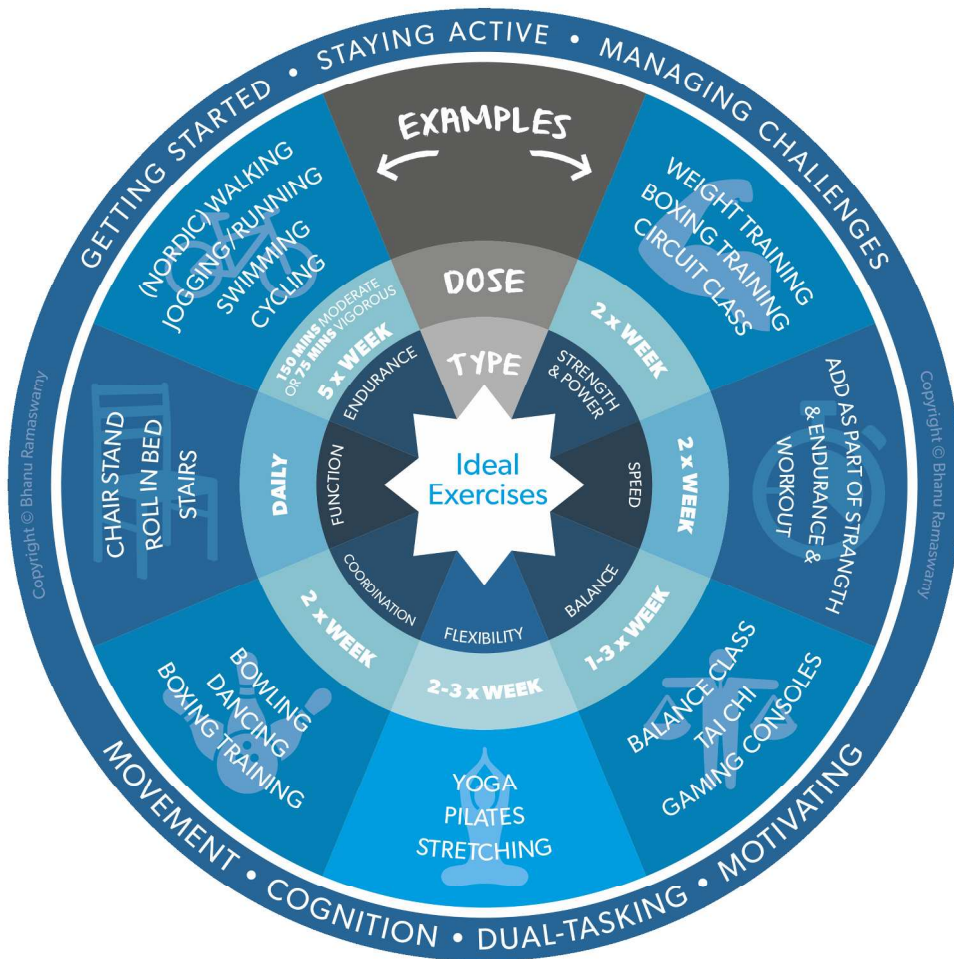


Figure 1: Types, dose and examples of ideal exercise for People with Parkinson's

Parkinson's Exercise Framework (for exercise professionals and health professionals)

Key messages for professionals to give the people they support and examples of exercise styles to focus on

| | Investing in exercise from diagnosis onwards | Staying active | Managing complex (physical) challenges |
|--|--|---|---|
| Focus | <p>Emerging evidence suggests that increasing exercise to 2.5 hours a week can slow the progression of Parkinson's symptoms, so:</p> <ul style="list-style-type: none"> • seek referral to an informed professional to discuss exercise and its benefits, the individual's physical state and motivation • exposure to an exercise-focused lifestyle (that is sociable and fun), using family, friends or Parkinson's networks, supports regular exercise behaviour • if symptoms are mild, this is the optimal time to improve physical condition to remain well, prevent inactivity and the complications of sedentary behaviour (weight gain, heart disease and metabolic disorders such as diabetes and osteoporosis) | <p>Keeping moving is important for people with Parkinson's, so:</p> <ul style="list-style-type: none"> • stay as (or more) active than at diagnosis and increase exercise targeting Parkinson's-specific issues such as balance and doing two things at once (dual tasking) • continue to keep the progression of symptoms to a minimum by exercising both the body and the mind (especially for memory, attention, and learning) • use the positive effects of exercise to better manage non-motor symptoms such as mood and sleep | <p>Movement, ability and motivation change over time, so:</p> <ul style="list-style-type: none"> • pay attention to specific physical functions that focus on daily activities such as getting up out of a chair, turning or walking safely • continue to maintain general fitness for physical wellbeing, finding ways to make sure this is kept up • prevent discomfort related to postural changes |
| Exercise style (bearing in mind fitness and any barriers to exercise such as travel or fatigue) | <p>Target postural control, balance, large movement (including twisting) and coordination through:</p> <ul style="list-style-type: none"> • moderate and vigorous intensity exercise to get the best performance from the body. Best done 5 x week in 30 minute bouts (can be built over time) • progressive resistance exercise to build muscle strength and power. Best results if done 2 x week • Parkinson's-specific exercise prescribed by health professionals such as dual-tasking and stretching for flexibility. Best results if done 2 x week • (Evidence from animal models that vigorous intensity exercise may have neuroprotective effects is in its infancy with humans, so more research is needed.) | <p>Target flexibility (dynamic stretching), plus slower exercise to control postural muscles for balance through:</p> <ul style="list-style-type: none"> • maintaining effortful exercise that pushes people according to their fitness levels • continuing resistance exercises • increasing balance exercises • increasing postural exercises • Parkinson's-specific review by health professionals | <p>Target better movement through:</p> <ul style="list-style-type: none"> • functional exercise (chair-based with the use of resistance bands) • supervised classes with a professional reviewing safety to perform exercise • home programmes to stay moving, avoid sedentary behaviour, reduce flexed position and the secondary effects of being less mobile |
| Examples | <ul style="list-style-type: none"> • Sport: racket sport, cycling, jogging, running and swimming • Leisure centre and other classes: aerobics, vigorous intensity training (such as boot camps with high level balance work), Nordic walking • Home DVDs or high intensity exergaming • Parkinson's-specific exercise such as PD Warrior, boxing training classes, the Parkinson's Wellness Recovery (PWR!) programme, some exercise classes run by the Parkinson's UK network | <ul style="list-style-type: none"> • Golf, bowling, (paired) dance, health walks, swimming • Flexibility with strength: tai chi, Pilates and yoga • Specific classes for people with Parkinson's such as LSVT BIG and balance and walking classes (run by the Parkinson's UK network) | <ul style="list-style-type: none"> • Specific classes for people with mobility and balance challenges, especially dance • Pedal exerciser • Resistance band workouts • Supervised balance and mobility challenge tasks • Seated exercise groups (some run by the Parkinson's UK network) |



Figure 3: Circuit class
203x152mm (300 x 300 DPI)

Review Only



Figure 4: Posture and balance class

203x152mm (300 x 300 DPI)

Review Only



Figure 5: Aquarobics and hydrotherapy

203x152mm (300 x 300 DPI)

Review Only



Figure 6: Green gym - pre monthly walk

203x152mm (300 x 300 DPI)

Review Only