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Citation: Ramaswamy, Bhanu, Jones, Julie, Baker, Katherine and Oliver, Beccy (2021) Methodology of exercise resources development for professionals providing services for people with Parkinson's: a technical report. *Physiotherapy*, 112. pp. 49-54. ISSN 0031-9406

Published by: Elsevier

URL: <https://doi.org/10.1016/j.physio.2020.10.004>
<<https://doi.org/10.1016/j.physio.2020.10.004>>

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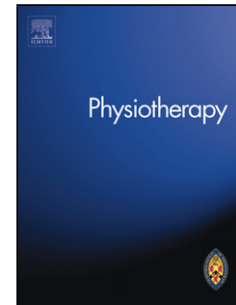
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Methodology of exercise resources development for professionals providing services for people with Parkinson's: A Technical Report

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PII: S0031-9406(20)30414-4

DOI: <https://doi.org/10.1016/j.physio.2020.10.004>

Reference: PHYST 1209

To appear in: *Physiotherapy*

Please cite this article as: Ramaswamy B, Jones J, Baker K, Oliver B, Methodology of exercise resources development for professionals providing services for people with Parkinson's: A Technical Report, *Physiotherapy* (2020), doi: <https://doi.org/10.1016/j.physio.2020.10.004>

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Methodology of exercise resources development for professionals providing services for people with Parkinson's: A Technical Report

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Abstract

The complexity of motor and non-motor symptoms seen in Parkinson's, with their variability and progressive nature, have a significant and potentially detrimental effect on mobility and subsequently quality of life for those with Parkinson's.

A considerable body of evidence now exists advocating the positive value of physical activity and exercise on both the motor and non-motor symptoms of Parkinson's, whilst limiting the impact and effects of the secondary complications. The literature is signposting to early adoption of higher intensity exercise, with reported benefits at a neurophysiological level, and a potential to influence a diminution in the rate of progression of the condition. It lacks clarity about structure of activity throughout the

course of Parkinson's, and occasionally raises conflicting information about the differences in physical activity and 'best' exercise.

This report describes the method for development of two Parkinson's exercise resources for professionals co-ordinated through the charity Parkinson's UK. The process uses the six-step Analytic Hierarchy Process to understand how the growing number of questions asked by people with Parkinson's, and by professionals about physical activity and exercise has informed: a) An Exercise Framework resource, which provides an understanding of what style of exercise might be beneficial, and just as significantly, takes into account the individual's changing needs and abilities over the course of Parkinson's, and b) An adaptable teaching template (PowerPoint Presentation) containing the supporting evidence for use by the exercise prescribing community.

Keywords: Parkinson's; exercise; resources; development; method

Introduction

In the light of growing literature supporting physical activity (PA) and exercise prescription for people with Parkinson's, Parkinson's UK have launched a series of online resources for the Parkinson's community. The materials provide guidance on 'when, why and how to start exercise' for different audiences.

People with Parkinson's form a small proportion of many professionals' caseload, so keeping abreast of the current evidence is challenging. Therefore, a two page summary in the form of a Parkinson's Exercise Framework for professionals, and an adaptable teaching template (PowerPoint Presentation) containing the supporting evidence have been developed for use by the exercise prescribing community including Exercise Professionals, Physiotherapists, and Occupational Therapists.

The resources provide a means of up-skilling professionals, enabling an educated and evidence-based conversation around the PA and exercise conversation with the Parkinson's population. The updatable resources ensure that professionals providing education to different audiences are disseminating consistent, evidence-informed messages about exercise and Parkinson's.

This article describes the methods by which resources for professionals were developed, how they might be used and updated in the future.

Rationale for the development of Parkinson's exercise resources for professionals

Evidence of the multiple benefits to health and well-being of exercise for long-term neurodegenerative conditions such as Parkinson's keeps amassing^[1,2], but creates inconsistencies in communication about what people should be doing, and what is 'best'^[3].

At diagnosis, the average person with Parkinson's can be 30% less active and slower than age-matched controls^[4]. People experience higher levels of mobility problems, depression and apathy; all barriers to participation in PA and exercise, particularly for those finding it difficult to be active^[5]. Motor and non-motor symptoms contribute towards high levels of sedentary behaviour, and some people with Parkinson's report being inactive for up to 70% of the day^[4,6].

People with Parkinson's who have started exercise perceive it as a means to take back control of their symptoms, as well '*fighting back*' against this incurable, and progressive condition^[7]. The right resources could promote participation in exercise, enhancing confidence and empowerment associated with exercise engagement in people with Parkinson's^[8,9], whilst creating a means of embedding PA in everyday routines to achieve the recommended 150 minutes of moderate weekly activity^[10].

A Core Team (the article authors) of an Exercise Professionals' Hub, a subgroup of the charity Parkinson's UK's Excellence Network was working towards the Parkinson's UK Strategy 2015 – 2019 goal of '*Empowerment to take control*', developing exercise-related resources that professionals could use and train others with. The materials made a distinction between the need to stay physically active, and the need to participate in exercise (a structured and planned activity) so people with Parkinson's might remain as fit and mobile for as long as possible. The Core Team was invited to be stakeholders in the

wider Parkinson's UK initiative to develop information for anyone seeking resources about exercise for Parkinson's.

Methodology for the development of a Parkinson's exercise resources for professionals

The development of the exercise resources is an iterative process (Figure 1), involving a wide group of stakeholders, and a shared-decision making method largely following the Analytic Hierarchy Process described for practical use by James Dolan^[11]. The six-step process is suitable for projects where decisions need to be communicated across a wide group of stakeholders with differing knowledge and needs, acknowledging preferences in a way that preserve the values of each, and finding ways to compromise on differences over the course of the process.

Please insert Figure 1 near here.

Step 1: Defining the decision elements towards a shared goal.

In response to growing members requests about new exercise research findings, the charity Parkinson's UK hosted a collaborative, co-production event in late 2015 to define a goal for a project looking into 'best exercise' for people with Parkinson's. Consensus was gained from discussions with exercise champions from the Parkinson's community, exercise novices, families, carers and varied professionals who prescribed exercise for people with Parkinson's to determine options to meet that goal.

Initially, dialogues were conducted through small group meetings and electronic conversation facilitated by a Parkinson's UK Project Officer with a remit to co-ordinate the project. Question stems were based on member requests centred on the impact of exercise on symptom management over the course of the condition, the ability to participate in different activities, and an 'ideal' in terms of exercise; responses were collated by the Project Officer.

Step 2: Constructing a decision model to review the evidence base around exercise.

There were two method strands at this stage. Most stakeholders continued to work with the Project Officer towards the goal of structuring 'best' exercise provision, how this might be met and disseminated; simultaneously, a Parkinson's UK Research Officer conducted a literature review around exercise to update the knowledge base following the last condition-specific guideline publication^[2]. The newer research publications determined that current guideline^[2] conclusions remained unchanged i.e. that exercise appeared beneficial; that no specific approach or style of exercise was superior to another; and there was no consensus on the optimal frequency, intensity and duration of exercise.

Clearer themes emerging from the newer literature however, supported the use of higher intensity exercise^[12,13], more effective when encompassing strength, endurance, balance and gait ^[14-16]. Group-based interventions were noted as favourable in supporting camaraderie, developing a sense of community and self-confidence^[8], all necessary components of enhancing adherence to exercise ^[5].

Step 3: Decompose the decision into smaller parts

A review of performance toward the project's goal by the Project Team highlighted different stakeholders' emphasis in their visions regarding the presentation of evidence and information. Not all required the same depth of knowledge, and people with Parkinson had different needs and requests than the professionals prescribing exercise.

In late 2016, the 'one size fits all' approach was abandoned. The resource materials were to be split into items for people with Parkinson's to work on, and into information for professionals who set exercise as part of their practice to develop.

The authors' remit now became to provide material for the latter group, including the newer evidence around exercise benefits for people with Parkinson's. The two-page

Exercise Framework idea developed from this (Figure 2), plus a more detailed educational template. Both were intended as dynamic tools, for review and update into the 5-year Parkinson's UK Strategy consultations, incorporating new evidence as it became available. Time frames demanded that the Parkinson's Exercise Framework for professionals was to be the first resource developed.

Step 4: Synthesis.

To test whether an exercise framework could meet the project goal of providing recommendations of 'best' exercise, members of the Exercise Professionals Hub drew up a penultimate draft of a framework. This was presented at a stakeholder event organised by Parkinson's UK. Stakeholders plus representatives from sports-based Higher Education Institutes and Sports England attended, commenting on the resource to inform the design of the final framework.

The agreement reached was that no definitive 'best' could be stated as individuals have differing preferences and needs, plus the evidence did not inform dosage and timing of exercise^[3]. The Exercise Framework therefore had to promote a pragmatic way in which professionals might support people with Parkinson's to live a sociable and active lifestyle through widely available provision of physical activity and exercise.

The first, and current Parkinson's Exercise Framework for professionals was published online, as part of a selection of educational materials for a wide audience in 2017.

In its current form the Exercise Framework is informed by a combination of systematic review evidence, primary research and expert opinion relating to popular and effective forms of exercise. People with Parkinson's persisted in their request for the inclusion of exercise they found beneficial, not all of which have been studied for impact, but their inclusion reinforced the practical applicability of the Exercise Framework.

The guidance broadly informs differing professionals advocating exercise how they should respond to the questions posed by people with the condition. It supports the prescription of individualised, and evidence-informed, timely exercise provision. The focus of exercise starts at diagnosis, continues over the course of the Parkinson's, and also when people find the condition challenging to physical and cognitive performance. It includes possible styles of exercise to meet individual need, and this in turn informed some additional graphic material produced for people with Parkinson's by Parkinson's UK.

Following the Exercise Framework release, reports were published in the journals of two physiotherapy Professional Networks for physiotherapists working with Parkinson's (AGILE, for physiotherapists working with older people, and ACPIN, for physiotherapists working in neurology), an article published for medical professionals^[17], and supported by regular Blogs for members of the Hub to share information of relevance to the delivery of exercise.

Please insert Figure 2 near here.

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Step 5: Analysis.

People with Parkinson's involved in the project expressed a wish to engage with professionals who were informed about the condition, with expertise in exercise prescription, and with a holistic approach to symptom management.

Professionals using the tool needed more detail about the dosage and timing of exercise recommended than was included in the Exercise Framework. They liked the three focus areas, but the physiotherapists found it harder to align what was presented without the accompanying evidence, compared with exercise professionals. The published Exercise

Framework could not reference all evidence gathered, so a means had to be provided in which to house the latest research about exercise for people with Parkinson's.

An analysis of the usefulness of the Exercise Framework started in early 2018. Emailed feedback was sought from those using and sharing the Exercise Framework through the Exercise Professionals Hub (collated by BR, BO). It was decided to develop an adaptable teaching template, communicated in the format of a Power Point Presentation (PPP) resource with the evidence base for exercise and Parkinson's at an annual Exercise Professionals Hub conference (2018).

Discussion was facilitated after the draft PPP was presented by members of the Core Team at this event (KB, JJ), and points raised were collected as flip chart/ sticky note responses. The collation process underwent further refining and a basic thematic analysis (KB, JJ), and results were presented as a new draft PPP at the next Exercise Professionals Hub Conference (2019). Consensus from the 2019 conference moved the Core Team's resource from development of the Exercise Framework to implementation of the evidence. The teaching template was published as an adaptable PPP for use in different contexts to inform fellow professionals. Some professionals only wanted to use the resource as a personal learning tool, whilst others use it as an up-to-date, off the shelf teaching material they could put their organisation's brand on for teaching.

Step 6: Making decisions, and/ or refining the analysis

At the time of writing this report, whilst Parkinson's UK are engaged in several strands of work into exercise for people with Parkinson's, this Core Team is in the process of:

1. Investigating the use of the resources, particularly the teaching template, in training.

The information will be updated according to its area of most use in accordance with the Parkinson's UK Strategy 2020 – 2024, with the idea of delineating different needs and roles of the health professionals and exercise professionals

2. Contributing to a Parkinson's UK document that describes how professionals could explore the discussions about physical activity and exercise with people with Parkinson's.
3. Considering how the different needs of physiotherapists and exercise professionals might need to be met in the next iteration of teaching materials.

Exercise Professionals Hub volunteers are undertaking the work. They decide how to delineate their roles, and timeframes based on their work priorities.

The purpose of writing this article has been twofold:

1. To ensure people are aware of the resources. For physiotherapists and exercise professionals new to the area of exercise and Parkinson's, the resources should be of benefit to their practice and in allowing consistency in their teaching. The Core Team can build on the links available through the UK Parkinson's Excellence Network regions and disseminate conversation through regional Network events, but a wider, and hitherto uninvolved group of professionals are necessary to promote this set of teaching materials. For those who already know about exercise benefits, it highlights availability of the tools to colleagues across the health, Leisure and Sports sectors.
2. For people to understand the methodology used when producing a much requested document and accompanying resource. Resource development is a long, ongoing process, taking four years to get this far. A shared-decision making method allowed for the wide scope of knowledge and practice of providers of exercise to people with Parkinson's. The rise of franchises across the UK delivering specific exercise programmes for people with Parkinson's has made it difficult to regulate marketing. There is also branding of well-established styles of exercise e.g. Boxing training, dance (such as ballet), Nordic Walking or Tai Chi as new for Parkinson's, as there is a research basis of the use of these techniques. In understanding this, people might

better understand the rational choices of the content of the current Exercise Framework.

Conclusion

The benefits of exercise are widely acknowledged as a way for people with Parkinson's to remain well and active for as long as possible through the course of the condition.

Research doesn't provide a definitive message about the style, dosage and timing of exercise of most value to people with Parkinson's. This is unhelpful for professionals prescribing exercise who have insufficient exposure to the condition to effectively manage the needs of those who present with a complex array of motor and non-motor symptoms, which also alter over the course of the condition.

The development of these resources for professionals has been timely, as exercise delivery has expanded across different sectors with little regulation. Although not able to answer the question of 'what is best', it at least helps professionals understand the changing needs of people with Parkinson's over the course of the condition.

The method by which two resources (a basic Parkinson's Exercise Framework for professionals and an adaptable teaching template with detailed evidence) have been developed highlight a process of marrying two occasionally opposing factors. The first is that of the stakeholders with Parkinson's requests for inclusion of styles of exercise from their experience of their personal benefits, and the second is a need to represent the evidence for exercise benefits through the delivery of a consistent message to groups of professionals, even when there is poor alignment to the evidence.

This project is ongoing, and will be updated during the Parkinson's UK 2020 – 2024 Strategy timespan. It is possible that in the future iteration, the different needs and roles of

the health professionals and exercise professionals will be delineated, and we might have greater insight into the use of technologies in supporting exercise delivery.

Resources: Parkinson's UK has produced a range of resources to help professionals spread a consistent message about exercise for people with Parkinson's.

The Exercise Framework can be accessed online at:

<https://www.parkinsons.org.uk/information-and-support/exercise>

Join the Parkinson's UK Excellence Network:

<https://www.parkinsons.org.uk/professionals/uk-parkinsons-excellence-network>

If interested in, or deliver exercise for people with Parkinson's, sign up for the informative Hub articles at: http://eepurl.com/bBF_QT.

Contribution of paper:

- This report provides a methodology to understand the developmental process of the Parkinson's exercise resources for professionals
- The Framework itself translates the evidence of exercise styles of benefit to people with Parkinson's into supportive focus areas that take into account the individual's changing needs and abilities over the course of the condition.

Funding: The project to develop the Parkinson's Exercise Framework was funded by Parkinson's UK.

Ethical approval: Not required

Conflict of interest: None

Acknowledgements:

Parkinson's UK staff involved in the 'Exercise' projects, particularly Matthew King, Charlotte Jackson, and James Lebus; the staff involved in the Excellence Network, particularly Fiona Lindop, Suma Surendranath, Daiga Heisters, and Risha Goswamy; participating members of the Exercise Professionals Hub and attendees of the stakeholder event for informing the development of the framework.

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Figure 1: The iterative process of development of the Parkinson's exercise resources

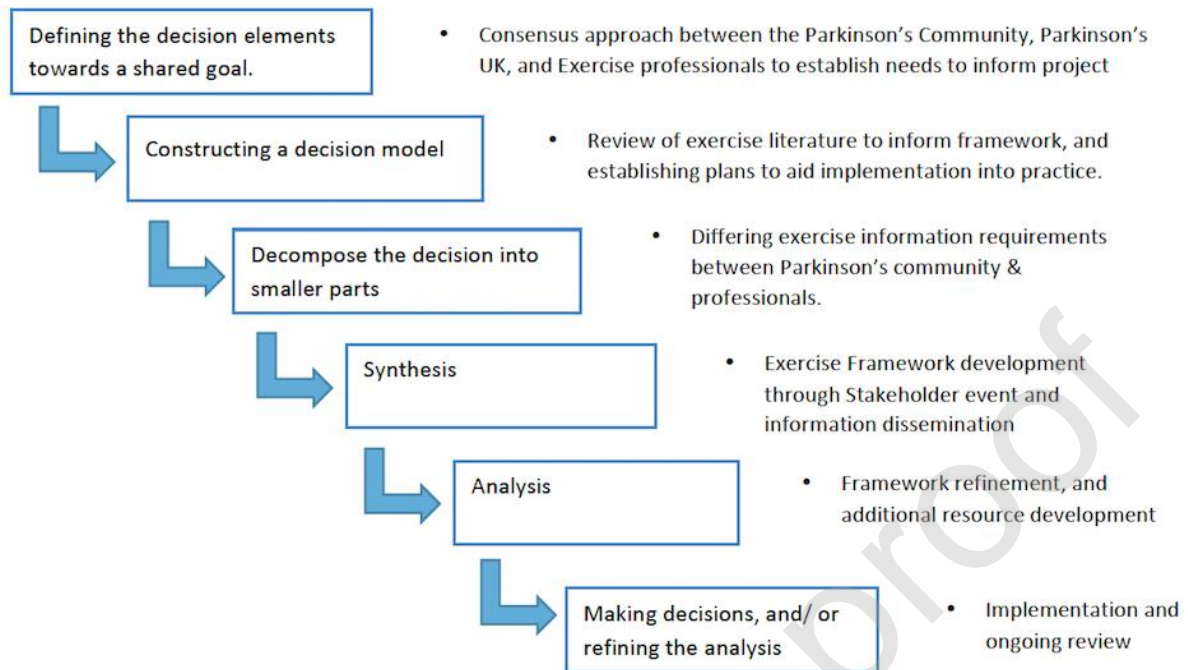


Figure 2: A single-page version of the Parkinson's Exercise Framework

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 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)

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