

## **Exploring Decisions to Undertake a Marathon and Adherence Challenges in a Novice Runner With Parkinson**

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# Exploring Decisions to Undertake a Marathon and Adherence Challenges in a Novice Runner With Parkinson

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## Abstract

Evidence endorses the benefits of more vigorous exercise for people with Parkinson's, particularly following diagnosis, yet is not clear which style is optimal. The authors share perspectives and decisions made as a physiotherapist (assisted by a sports and exercise science student) and a novice runner with Parkinson's in his late 50s, respectively. The exercise goal chosen by the runner (the case report participant) to minimize the degenerative effects of the progressive condition was to complete a marathon. **Methods:** This coauthored report evaluates the participant's progress utilizing physical fitness assessment data plus reflections on his training regime and notes from training diaries for the year before and after the marathon. **Results:** The participant received nutritional advice for weight management as exercise increased and physiotherapy for injuries from mounting activity level on Parkinsonian muscle tone. Fitness and function improved or were maintained (leg power, flexibility, timed functional walking, and balance). Most, however, returned to baseline within 6 months following the marathon as training intensity dropped. **Conclusions:** Physical function can be improved or maintained in individuals with neurodegenerative conditions with correct exercise and nutritional advice. The participant's choice of running was based on recommendations for condition maintenance and not enjoyment, so adherence and completion of the marathon goal required professional, family, and technological support.

## Keywords

Parkinson's (neurology), exercise adherence (behavior), physical assessment, marathon

## Introduction

I was diagnosed with Parkinson's in July 2009 aged 53. On 13 September 2014 my wife and I joined over 4,000 runners for our first marathon, the 22nd Jungfrau Marathon in the Swiss Alps...in great weather, spectacular views of my childhood, and fantastic organisation—and a tough course climbing over 1600 metres!

Chris, Personal journal entry (2015)

## Parkinson's and Exercise

Parkinson's<sup>1</sup> is the second most prevalent neurodegenerative condition in the United Kingdom (1,2). It is increasingly diagnosed in younger people and in proportionately more males (1,2). This younger cohort includes those most likely to take up or still be doing sporting activities or exercise (3,4).

Preliminary diagnosis is based on presenting motor (movement) signs (bradykinesia, rigidity, tremor), and current intervention is mainly through drug therapy to temporarily manage the action of decreased stores of the

neurotransmitter, dopamine (1,2). Dopaminergic action includes movement control and impacts on the brain's movement-based reward system, affecting motivation and adherence to exercise.

The far-reaching benefits of exercise, evidenced for helping alleviate motor and nonmotor symptoms and improving the dopaminergic system (5,6), are creating interest in the prescription of physical activity. Interventions of varied intensity and style are advocated such as boxing (7,8), cycling (9), Nordic walking (10), walking (11,12), dancing (13–15), and balance-specific functional

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exercise (16,17) but do not consider the management of individual traits (18).

Commencing, maintaining, and increasing exercise are significantly more beneficial in those newly diagnosed than those starting later (19,20). However, there is neither clear messaging of what would be “best” for an individual nor how professionals might take account of differing presentations of Parkinson’s from issues such as age at diagnosis and symptoms at onset.

This feature is written from the combined perspectives of a physiotherapist (first named author) and a person with Parkinson’s (second named author and case report participant) to enhance a professional’s understanding when prescribing exercise and assist those with Parkinson’s attempting such training. It uses information from fitness assessments, plus a journal kept by the participant, Chris, for 23 months pre- and postmarathon. Progress, challenges, and solutions to maintain motivation and adherence are explored in relation to Parkinson’s.

## Training and Assessment

### *Chris’s Motivation for a Marathon*

Chris was stable on antiparkinsonian medication when training started, had recently resigned from a stressful full-time (desk) job, and was actively seeking part-time employment. In autumn 2013, he and his wife identified 4 goals: taking control of his condition in the face of relentless decline (he had read that the rate of degeneration would increase after 5 years), spending positive time together while his life quality was good, choosing a significant personal challenge (the marathon), and increasing fitness to hopefully reduce medication.

Although Chris’s wife was a hardened runner, she had never attempted a marathon; Chris had only ever done a short fun run with the kids! They decided on the Jungfrau Marathon as Chris knew the area well and the route would be sufficiently challenging to keep focus.

### *Challenges and Progress*

**Prefirst assessment.** Chris utilized an Internet-researched plan to start marathon training with a key aim of 30 minutes mixed jogging and walking, 3 times a week, gradually increasing the jogging component. He writes:

From the beginning I got a pain in my left chest when running. I was concerned because I believed there was something wrong, perhaps even with my heart, and that it was best not to push it. . . . I did not want to stop my activities so early on. I decided to focus my exercises on spinning and stretching but feared I was already failing at the first hurdle.

Early in the training Chris met BR, a physiotherapist volunteering as exercise coordinator for the Sheffield Branch of Parkinson’s UK. She clarified that exertion-related discomfort is not unheard of in exercisers with Parkinsonian-

rigid musculature restricting rib cage expansion to match lung volume demand but still requires the exclusion of cardiac pathology. A General Practitioner (GP) review and echocardiograph provided an all clear, so BR offered fitness advice and assessments in Sheffield.

As weight loss can be an issue for people with Parkinson’s (21), BR involved KH, a Sheffield Hallam University (SHU) Sports & Exercise Science student, who gave Chris nutritional and technological advice and help with the fitness assessments to ensure optimal energy levels and muscle quality.

**The fitness assessment.** Chris (as just under 60 years old) formally consented to act as a test subject for physical tests BR was developing for older exercise participants in Sheffield with Parkinson’s. This included a recommended fitness testing program (22), 2 additional specific timing tests, plus a postural test and lung function tests, as flexed posture and a decrease in lung function can cause serious problems in the long term (23).

The assessment was managed through a third sector charity with no formal ethical approval required from the SHU Research and Ethics Committee. Chris recorded his exercise activity from the start (Table 1).

Baseline fitness results prompted KH to recommend he and Chris monitor progress toward the first race using a running (24) and a separate fitness app (25), chosen because they could both be accessed remotely and converted to analyzable graphs. This allowed nutritional intake (gradual increase in calories to match physical demand) and exercise to be adapted through online discourse of shared observations.

To Chris, the tangible sign of progress was his first 10 k race, finishing in 61 minutes:

It was faster than expected, and I felt quite well throughout the run and afterward.

Chris’s Parkinson’s, defined by his age at onset (under 55) as younger onset, has characteristic traits of increased limb tone of a dystonic (cramp-like) nature (26), which can impact on activities. He experienced no significant pain or injuries until the fifth month when activity levels rose significantly and the increased tone generated pain on his right lower limb, especially the foot. A local sport physiotherapist recommended a period off running, showed him how to tie his laces for longer runs, and BR taught foot stretches useful for this type of dystonia.

### *Months 7 to 12*

By late June, an unproblematic right foot X-ray and improved pain meant Chris restarted training increasing distances by 3 k every week. He and his wife walked in Snowdonia, ran the Tara Kinder 10 k (60 minutes 15 seconds), and the Worcester Half Marathon (2 hours 11 minutes):

**Table 1.** Chris's Activity Level Records.

Recorded items	Prefitness Assessment Months 1-2	From 1st to 2nd Assessment Months 3-5	From 2nd to 3rd Assessment Months 6-8	From 3rd to 4th Assessment and in Last Month Premarathon	From 4th to 5th Assessment	To New Goal
Dates	October 16, 2013, to December 13, 2013	December 14, 2013 to February 13, 2014	February 13, 2014 to June 05, 2014	June 06, 2014 to September 13, 2014	September 14, 2014 to April 02, 2015	April 03, 2015 to September 13, 2015
Weeks	9	12	12	14	29	25
Hours	8 hours 30 minutes of jogging/walking, 0.9 hours/week	22 hours of jogging/walking, 1.8 hours/week	14 hours of running and walking, 1.2 hours/week	More than 47 hours of running, 3.4 hours/week	0.2 hours/week	1.4 hours/week
Distance	85 km, 9.4 k/week	222 km 18.9 k/week	143 km, 11.9 k/week	392 km, 28 k/week	1.5 k/week	8.2 k/week
Comments	Jogging mainly treadmill	Started outdoor runs; cumulative activity of 308 km in 36 hours	Cumulative activity of 451 km in 45 hours	In his last month, Chris did 100 km of walking and running in a fortnight	Mainly walking, occasional run	Brisk walking

... a good result for my first half marathon, running well at the beginning, later increasingly walking.

Chris's main challenge was:

... to eat the recommended 3300 calories a day with sufficient fluid to maintain energy, weight, and hydration.

KH managed this by reviewing consumption and adding 2 additional high-calorie and protein-heavy snacks between Chris's 3 daily meals. After a positive fourth assessment, a 30 k session in early September caused recurrence of his right-hand "Parkinson's" side pain (intriguingly briefly experienced on his left). Distraction techniques (humming and counting in Swiss German) kept him going, but the aim altered to "finishing the marathon," rather than his hoped official time of 6.5 hours.

### *The 22nd Jungfrau Marathon (September 13, 2014)*

Chris and his wife arrived a week before the race to adjust to the altitude and explore the route. They started fast, with Chris achieving a 10 k personal best of 57 minutes.

At 7 k I began to feel pain in my right knee ... and began to walk more. After 10 k I fell behind [my wife] and the decision to split up was swift so one of us would finish within the official time limit. I was in bad shape and had 27 k to go but now the pressure mechanism came into its own more decisively than I had expected. I visualized trying to explain to friends and supporters what had stopped me from finishing ... and for the next 27 k I never considered giving up again—the only question that remained were how and when I would finish. 8 hours and 40 minutes after the start and with [my wife] and [daughter] yelling, I arrived at the finish with [my son] who had walked the last 13 k with me. [My wife] and I held the sQuad<sup>2</sup> flag aloft on Kleine Scheidegg (Figure 1).



**Figure 1.** Chris and his wife holding the sQuad flag aloft on Kleine Scheidegg.

## **Motivation and Adherence**

Chris's main motivation came from 3 sources:

1. His wife, a retired physiotherapist:  
... the most important source of support throughout. She motivated me and suggested solutions to the string of issues and concerns that bothered me.
2. Specialist professional support:  
BR and KH were intrigued whether I would stick with the training but their involvement and advice played a key role in helping me do so.

### 3. Establishing a personal “pressure mechanism”:

... The closer the race and harder the training, the more pressure I needed to stick with it. The more people I told, the more support I received, the greater the commitment to achieving the challenge. This fear of loss of face exerted the strongest pressure on me. Turning this into positive achievements was the main mechanism that made me stick with the task.

## Assessment Results

Chris’s overall fitness and function improved or were maintained (Table 2), but most returned to baseline within 6 months as expected for individuals with degenerative conditions as training intensity dropped (23). The 6-minute walking distance test remained above average (27) and continued to improve postmarathon.

## Parkinson’s-Specific Issues

Some challenges and issues Chris faced may seem similar to those for any novice runner. Understanding when to push someone with a neurodegenerative condition through injury and what to monitor as behavioral traits affecting motivation and adherence however require knowledge of Parkinson’s. Chris’s personal diaries proved useful for detecting contradictory statements, excessive behaviors, or extreme emotional states. We monitored 3 issues:

### *Compulsivity and Impulsivity*

Antiparkinsonian medications can stimulate certain neural receptors and lead to addictive behavior (28). Although single activities seem harmless, cumulative factors can encumber the person in terms of time, money, and stress, also affecting family relationships. Diary entries arousing suspicion from otherwise innocuous statements include Chris’s decision to take on an unusual challenge for a normally cautious person, recording that his decision to run a marathon:

... may have been influenced by a less than full appreciation of all the implications.

The prescription of a dopamine agonist raises awareness of impulsive action, undertaking such a huge task into the longer term. Chris notes:

It’s clear from the research that the only thing everyone agrees helps Parkinson’s is exercise. I started doing some exercise, but I’ve always had a problem with sticking with sporting activities for any length of time...

The behavior traits of compulsivity often match characteristic traits of the person, in Chris’s case his meticulous nature. He navigated and read through a “whole industry around long-distance running.” His logs illustrate his

program and training regimen with analyzed marathon route, divided into manageable periods of walking and running.

Although in itself this is commendable, the compulsion to gather data and review the challenge required monitoring. Addictive behavior is not always a bad thing, and despite his anxieties, it contributed to adherence:

I had virtually constant doubts about my ability to finish the marathon but I did not let that interrupt or stop my training.

But fixation was an issue, although taking his mind off Parkinson’s (a positive for Chris):

It really preoccupies me... From when I wake up to when I go to sleep I’m thinking about how on Earth I’m going to finish that marathon.

This should alert a professional that once this goal is completed, Chris will need another point of focus to maintain adherence to exercise.

### *Psychological Changes*

These are not uncommon in people with Parkinson’s, particularly emotions such as anxiety (29) and perseveration (repetition of a specific response) (30). The point is to recognize the extent to which they manifest in a person with Parkinson’s. Chris records:

A strong urge to stop running without clear reason beyond feeling an increasing inevitability of doing so, keeping walking and then restarting quite soon.

### *Cognitive Changes*

Cognitive changes are experienced by people with Parkinson’s even in earlier stages, affecting planning, learning, memory, problem solving, attention, and hence the ability to multitask (23).

Many times, a person finds a solution, as in examples chosen of Chris’s altered cognitive ability, indicating areas of difficulty:

My inability to run and talk at the same time and my preference to run on my own linked to a Parkinsonian inability to multitask...

After 6 months I was now also paying more attention to my mental focus and stopped running to music.

Difficulties in absorbing new information making it difficult, for example, to monitor intake of specific nutrients.

## Medication

Medication is not mentioned as an issue for Chris, although some people experience periods of depletion that negatively

**Table 2.** Summary of Fitness Assessments.

Assessment Tasks	First Assessment: December 13, 2013	Second Assess- ment: February 13, 2014	Third Assessment: June 05, 2014	Fourth Assessment: July 28, 2014	Fifth Assessment: April 02, 2015
Physiological tests					
Weight	66.3 kg	66.2 kg	64.8 kg	66.9 kg	69.8 kg
Height	183.60 cm	Not remeasured	183.2 cm	183.20 cm	184.4 cm
BMI	19.6	19.6	19.3	20.0	20.4
Blood pressure and heart rate (preexercise) $\times$ best of readings	125/75-86 bpm	149/73-63 bpm	120/78-83 bpm	133/78-84 bpm	125/73-68 bpm
Posture (tragus to wall) for monitoring of postural deterioration	Right 14 cm Left 14 cms	Not retested	Not retested	Right 14 cms Left 14 cms	Right 13 cms Left 14.5 cms
Lung function					
PFR	530-574 L/min	510-576 L/min	540-582 L/min	534-564 l/min	528-552 L/min
Peak cough flow (monitor cough inadequacy)	448 L/min (good)	Not retested	Not retested	Not retested	PCF-492 L/m
FEV1/FVC ratio	79% (0.79) (good)	75% (0.75)	75% pre to 77% posttest	77%-78% pretest	76%-78% pretest
Hydration (total body water kg/total body weight kg $\times$ 100)	64.5% (good)	64.5%	64.2%	63.9%	Not tested
Functional fitness—Based on recommended tests for older people and people with Parkinson					
30-Second chair stand (>8) (leg power and endurance)	16	21	20	23	20
Chair sit and reach (flexibility)	Right 12 cm Left 13 cm	Right 13 cm Left 12 cm	Right 11 cm Left 10.5 cm	Right 9.5 cm Left 9.0 cm	Right 14 cm Left 20 cm
Back scratch (flexibility)	Right top touched left Left top 18 cm away from right	Right 3 cm overlap Left 16 cm away from right	Right 3 cm overlap Left 8 cm away from right	Right 3 cm overlap Left 0.5 cm overlap	Right 6 cm distance Left 17 cm distance
8 foot up and go (< 15 seconds; function)	Best of 3 = 4 seconds	Best of 3 = 3.59 seconds	Best of 3 = 3.85 seconds	Best of 3 = 3.13 seconds	Best of 3 = walk 3.96 seconds; run 3.11 seconds
Handgrip strength (> 40) (strength and upper limb function) Best of 3	Right 35.8 kg Left 41.1 kg	Right 40.1 kg Left 40.4 kg	Right 39.9 kg Left 40.0 kg	Right = 40.9 kg Left = 40.9 kg	Right = 43.5 kg Left = 40.9 kg
Single leg stance (60 seconds; balance)	Managed 60 seconds each leg	Managed 60 seconds each leg	Managed 60 seconds each leg	Managed 60 seconds each leg	Managed 60 seconds each leg
6-minute walk test (endurance)	652.2 m	709.9 m	716 m	850.25 m	900 m
Forward flexion (25 at 50 bpm; Parkinson-specific test of synchronicity)	21	Full 25	Unable to complete more than 11	Full 25	Full 25
Stepping (20 each leg at 50 bpm + no loss of height) (test of synchronicity)	Full 20 + cues	Full 20 no cues	Full, 20 no cues	Full, no cues	Full, no cues

Abbreviations: BMI, body mass index; PFR, peak flow rate; FEV, Forced expiratory volume; FVC, Functional vital capacity.

affect movement quality (26). Just before the marathon, Chris obtained a prescription for fast dispersible antiparkinsonian medication. However, he felt he did not need it, not even to counter pain (possibly tonal in nature), an issue of further education for Chris had he chosen to carry on running.

### Postmarathon Reflection

Chris records that:

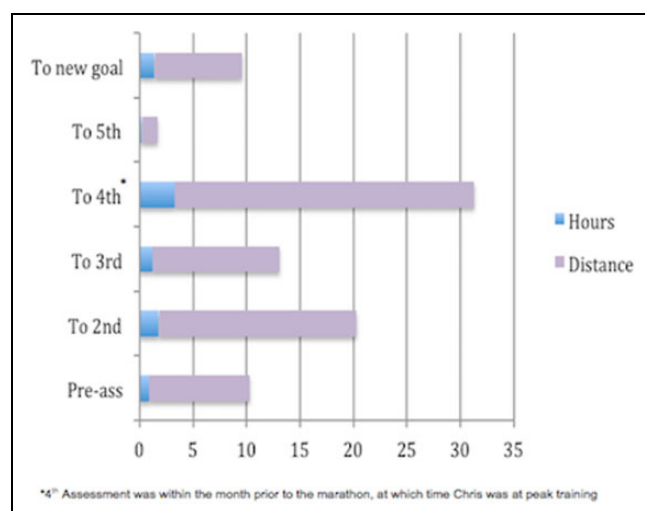
... relief and pride at having finished the marathon was great.

While still on holiday with significant leg pain and sleeplessness, he and his wife identified:

... next steps: keeping up a good level of stretching exercises, gym, and running, with at least one 10 k and one half marathon a year; and finding and focusing on a new challenge together.

Back home however, Chris' motivation was not maintained despite strong support and encouragement from his wife and friends, following the run raising over £3000.00 (31).

This decline in activity is illustrated in charted exercise over 2 years (Figure 2) but is rising again, as Chris



**Figure 2.** Performance data comparing hours exercised and distances run per week.

recognized a worsening of symptoms, exacerbated without exercise.

Chris has settled on 2 facts:

1. Walking is better for me than running.
2. Having a (challenging) goal is important.

Chris had a significant birthday in 2016 and set another impulsive goal to “Walk 60 k in a day”!

## Conclusion

People with Parkinson’s need full support to exercise or partake in sport. Although a limitation to case reporting includes the inability to establish a cause–effect relationship (32), the in-depth narrative of this feature enables professionals and people with Parkinson’s alike to understand some of the motor and nonmotor symptoms affecting motivation and adherence using the experience of a man with Parkinson’s running his first marathon. Chris’s goal was achievable only through family and friends’ support and the utilization of varied means including Internet-sourced training program, professional intervention, and technological monitoring to enable exercise to become part of a daily routine.

Professionals with experience in behavioral and motivational health practice and an interest in Parkinson’s would be well placed to implement the procedures described in this case report and support those with the condition.

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## Notes

1. In 2010, Parkinson’s UK implemented a rebranding including a name change to clarify its organizational values. The word *disease* was removed for its negative connotations and stigma. *Parkinson’s* is recommended for use in preference to *Parkinson’s disease* when describing the condition or referring to people with Parkinson’s.
2. sSquad was formed in Derby in 2010 by people with Parkinson’s of working age and their partners/carers. See also: <http://www.parkinsons.org.uk/local-support-groups/regions/east-midlands/derby-working-age-group-squad>.

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**Christian Johnson** has worked in information and research for local, national and international charities and community organisations. He is a founder member of the East Midlands Research Support Network and of the Derby sQuad Working Age Group of Parkinson's UK.