BEING ACTIVE WITH PARKINSON'S

Helping people with Parkinson's to be active, feel energised and live well





Caroline Rassell CEO Parkinson's UK.



As the CEO of Parkinson's UK I am delighted to welcome you to our new guide - Being Active with Parkinson's.

At Parkinson's UK we know how important it is for the community to be active, and our intention at the charity is to continue to invest in supporting people with Parkinson's to access as many opportunities to be physically active as possible.

This guide has been produced with people with Parkinson's, activity providers and healthcare professionals, and it's designed to help everyone learn how important it is to be active. I hope you find this guide useful and enjoyable, and it helps you to break a sweat, lift your mood, and live well with Parkinson's."



Dr Jonny Acheson, Emergency Medicine Consultant Leicester Royal Infirmary.

Director of Engagement and Communication Parkinson's Excellence Network.

Jonny also has Parkinson's.



The message is simple, physical activity is good for Parkinson's. The implementation of the message is the challenge. Apathy and fatigue are the nemesis of people with Parkinson's.

Regular physical activity will help your mood, your energy levels and your motivation but you need to plan it. You need to make sure it works around your medication timings and be careful that it is not so intense or tiring that you get thrown off course.

When I undertake physical activity and have worked up a sweat, I imagine the neurons in my brain reaching out to one another to try and join together. I feel better for doing it, my mood is better, my outlook is better, my symptoms are better controlled and I am motivated to keep going.

Physical activity will mean different things to different people. There should be a focus on muscle strength, flexibility and general fitness. You should do something that you enjoy, that is social and that you will want to keep doing.

We can all make positive choices, now is the time."



Janet Kerr, person with Parkinson's.

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After my Parkinson's diagnosis, my exercise journey began with a beginner's 30 day yoga challenge I found on YouTube. This helped me immensely with mobilising my stiffened joints and muscles. After that I continued with yoga but then introduced Pilates; this improved my strength. Due to pain, I struggled with impact exercises, and I read that cycling is good for people with PD, so I dusted off my bike and gave it a go. I was initially concerned that balance would be an issue, but, to my surprise, it wasn't. In fact, I believe that cycling has improved my balance as well as increasing my stamina and fitness.

I soon found that when I did higher intensity activity, I began to feel an endorphin based euphoria. I then introduced a strength training workout using a kettlebell. In a matter of weeks, I noticed a positive difference in my well-being, posture, strength and flexibility. Everyday functioning and daily tasks had become easier. I was fighting for 'movement' and exercise helps me win that daily battle against stiffness and rigidity."

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Reminding myself how I would feel if I didn't exercise helps me stay motivated to stay active." - Caroline



BEING ACTIVE WITH PARKINSON'S

Why is it important to be active?

Research has shown that regular, moderate to vigorous physical activity can help relieve some of the motor symptoms of Parkinson's, as well as improving overall mental and physical wellbeing.

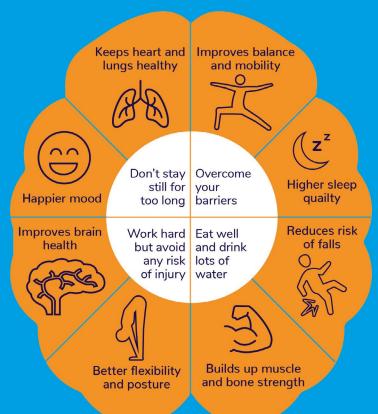
The physical benefits of being active can include:

- better muscle and bone strength
- improved flexibility and joint mobility
- improved balance and a reduced risk of falls
- higher energy levels and better sleep
- lower stress levels and lower blood pressure
- reduced risk of developing other health problems such as heart disease, stroke, diabetes, osteoarthritis, dementia and some cancers.

Being physically active can also bring benefits to mental wellbeing, including:

- improved confidence and self-esteem, especially from the social benefit of being active with others
- improved cognitive ability, helping your brain work more efficiently, so you can learn and remember more
- reduction in anxiety and depression, and increased happiness, especially if you can be active outdoors.

PHYSICAL ACTIVITY FOR PARKINSON'S



Remember:

- At least 2.5 hours of physical activity per week is recommended.
- Regular physical activity will improve your quality of life.
- Any activity is good for you (it is as important as medication).
- Do what you enjoy.

Suggested activties:

- Fast walking
- Yoga
- Resistance training
- Tai Chi
- Dancing (rhythmical, tango)
- Pilates
- (rnythmical, tango)
- Swimming
- Running (treadmill training)



Where do I start?

The thought of starting to become physically active or getting back into it can be overwhelming. It can feel like something difficult or boring, or something only done in a gym. The good news is that you can be active doing the things you enjoy. You're not alone, we're here to help.

Getting started safely

Being more active is one of the healthiest decisions you can make, but it's important to do it safely. If you haven't been active for a long time, or have other long term health conditions, talk to your GP before starting.

Start slowly and build up steadily, increasing what you're doing over time and remembering to listen to your body. For example, try spacing out what you do in 10 minute blocks during the day.

It is vitally important to remember that Parkinson's can vary day to day or hour to hour. Do not feel guilty if what you're able to do fluctuates; this is to be expected with so many influencing factors such as sleep, hormones, medication, and mood.

Prevent injury and discomfort by warming up before being active, cooling down afterwards, and keeping water and medication handy. Try and commit to being active for at least 3 to 4 weeks so that it becomes a habit. You'll find this much easier if you do things you enjoy.

All physical activity can be beneficial and any increase will be good for you. The key to habit building is little and often, building up gradually, but trying to challenge yourself.

Physical activity can include everyday things you may already be doing like walking, gardening, and climbing the stairs.

Find activities that raise your heart rate or focus on flexibility, balance, strength, and multitasking.

The most important thing is choosing something that you find enjoyable and achievable.

Here are some quick tips for getting started:

- Find activities that include a mix of intensity and skill.
- Learning a new activity (such as Tai Chi, boxing or yoga) helps improve your thinking as well as mobility.
- There isn't one activity that best fits everyone, focus on what brings you joy.
- Set yourself goals that challenge you but are realistic enough to keep you motivated.

INTENSITY AND WHY IT MATTERS

Julie Jones, Chief Scientific Officer and Parkinson's UK Clinical Academic Fellow, explains why it's important to get your heart rate up and break a sweat.

Different types of physical activity and sport are beneficial for people with Parkinson's, however more recently research has demonstrated that moderate to high intensity exercise is of particular benefit. High intensity exercise has been shown to have a positive impact on the health and development of neurons within the brain and enhance the efficiency of neuronal activity. This is very important in a condition such as Parkinson's, where the death of neurons results in a range of symptoms.

High intensity activity raises your heart rate, gets you out of puff, and makes you sweat. As a guide you should still be able to speak, but you may not manage a full sentence. Current guidelines suggest we should be aiming for 30 minutes of moderate to high intensity activity, five times a week

These guidelines are useful but many of us will need time to build up to this target. Set yourself a goal and gradually increase the time you spend moving at a higher level. For example, on a 30 minute walk, try increasing your pace for 2 minutes, then return to your normal pace for 5 minutes and repeat. Over time, you can increase the duration spent walking at a higher pace.



Don't get too comfortable

It's important to try an activity or programme that challenges you, keeps you motivated and prevents plateaus. This can occur when the body adjusts to the demands of the activity. Assessing yourself and increasing your activity, when you feel it's becoming too easy, can help avoid a plateau. This applies to everyone no matter how active you may be.

Small changes can add up to give significant results:

- increase the number of repetitions of an exercise, if you can comfortably do 10 lunges then increase to 12 lunges
- increase the weights used in resistance workouts in small increments
- increase the duration of exercise or activity by a few minutes at a time
- add inclines (hills and steps) to your walking route.

What should I be doing?

It's understandable if you read all this information and still feel a bit lost about what you should ideally be aiming for. Here are different types of activities to incorporate into your routine, and how often you should try and achieve them.

Aerobic 30 minutes, 5 times a week

Aerobic activity will raise your heart rate and also help improve muscle tone. For maximum benefit in people with Parkinson's, research suggests that aerobic activity should be at a moderate to high intensity - so try and break a sweat! This can be performed continuously or spread out throughout the day such as three 10 minute power walks.

What counts as aerobic activity?

- Walking: walk with a friend, join a walking group, or search online for local 'health walks'
 which are led walks that support people who are starting to get active.
- **Cycling**: a low impact option that also has the benefit of getting you outside. If you're not confident cycling outside then a stationary bike is a great alternative.
- **Dancing**: a fun and social activity with lots of options such as salsa, Zumba, and line dancing.
- **Swimming**: another great low impact option for those with joint issues or back problems, but do try and swim a little faster or longer each time you go.
- Walking football: this is a great activity for those who can't run as much any more but who enjoy a team sport to get their heart rate up.

Coordination and balance 30 minutes or more, 2 times a week

Balance impairment and falls can be significant problems for people living with Parkinson's, so balance training is crucial. A yoga or Tai Chi class can be a great way of meeting new people while also working on balance. For a low cost option, there are lots of great balance programmes free online.

It's also really easy to incorporate some simple poses into your everyday routine, such as standing on one leg as the kettle boils.

Activities that require coordination not only get us moving but can also improve cognitive ability. As well as muscle strength, flexibility, and cardiovascular health, being active can cause positive changes in the brain. When you start a new activity your brain is also learning the movements. This process of teaching your brain a new pattern is called neuroplasticity.

To flex your brain abilities you might want to try a skilled activity, such as dancing or boxing, or a body conditioning class, that requires you to keep in time and mirror movements. You can also add a cognitive challenge to a walk or run, such as counting down from 100 in 7s.



Strength

2-3 times a week

Strong muscles are vital to maintaining and improving the ability to perform daily tasks. You can work to strengthen muscles anywhere and at any time, it doesn't always have to be in a gym. If you're new to strength training it's important to start slowly to avoid injury.

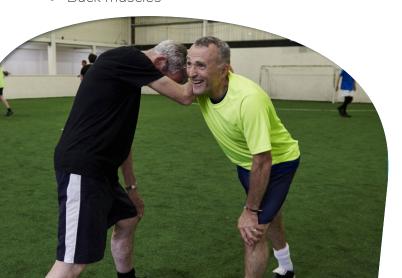
Strength training can include lifting weights or using machines at the gym. However, it can also mean using a simple resistance band, or even your own body weight for great results. Something like a plastic bottle filled with water or tins of beans also make great makeshift weights at home. You can also search for terms such as 'no equipment resistance workouts' on YouTube where you'll find plenty of free resources.

Here are some tips for starting strength training:

- Perform at least one set of each exercise, focusing on different areas of your body.
- Each set should contain 10–15 repetitions. If 10 starts to feel easy, add a few more.
- Don't work out the same muscles on consecutive days; muscles need to recover in order to become stronger before training again.

It's great to try and work the whole body, but people with Parkinson's should make sure to include the following muscles which help to combat posture and strength changes:

- Core muscles (this includes your pelvic floor muscles)
- Thigh muscles
- Buttocks
- Back muscles



Concentrate on slow movements and good posture when doing this kind of activity.

Remember to stop any exercise that causes you pain and if you're new to strength training it is best to get help from an exercise professional first.

Flexibility 10-20 minutes, daily

Regular stretching is important to help ease muscle rigidity, as well as keeping you flexible. People who are more flexible tend to find everyday movements easier.

Stretching is a really excellent way to start your day. Not only will it warm up your muscles but you will mentally benefit from taking that time to focus on your wellbeing first thing in the morning. Try the following:

- Dynamic stretching: start with these to warm your muscles up and help avoid injuries.
 Movements like arm circles, hip circles and spinal rotations are great for waking up your muscle groups.
- Static stretching: next add some stretches that you hold in position for 10-30 seconds.
- Try to perform 2-4 repetitions of each stretch to get the most benefit.

There are lots of brilliant flexibility apps and free online routines that you can follow.

The muscles that tend to become tight for people with Parkinson's are those that bend and rotate the joints. Be sure to include these body areas in your stretching routine:

- Chest
- Shoulders and elbows
- Back of the thighs (hamstrings) and knees
- Front of thighs, especially front of hips
- Calves
- Front of wrists and palms
- Lower back and neck

Your stretch should feel like a gentle pull. Do not stretch to the point of pain, you should only feel slight discomfort.

STAYING ACTIVE AND MOTIVATED





"Table tennis is one of many activities I do to help manage my Parkinson's symptoms. It improves hand-eye coordination, and stimulates mental alertness and concentration which are all impacted by Parkinson's.

It requires me to move fast over short distances which helps to improve both large and small muscle movements but it's easy on my joints. Table tennis is a great way to help maintain leg, arm and core strength, which is important as Parkinson's impacts my range and amplitude of movement.

It's also just a great way of burning calories while having fun and having social interaction, which benefits my mental health."



Jagdeep Singh Aujila boxes

"My consultant said being active is the best thing and even mentioned boxing, so I started to research just how it benefits people with Parkinson's. I'm all for being active and it will bring a positive outcome to anyone with an illness.

The benefits of getting active definitely outweigh the negatives. No matter what illness you have, just do what works for you.

My boxing class has also been a great opportunity for men with health issues to speak to each other, something men don't generally do. A problem shared is a problem halved and it's good to make people aware they are not the only ones in this position."

Developing good habits

Make it as easy as possible to start, and as hard as possible to avoid, being active. Plan your activities and set goals for the future that you can work towards to keep you going. It's often worth joining a long term programme to keep you accountable and help build up a routine.

At first, focus on the frequency of activities to help them become habits. It's better to do three 10 minute runs a week than an hour long run every 3 weeks! Habit building relies on small actions that make everything easier.

Putting your clothes out the night before or setting up your equipment in advance will increase your chances of actually doing it.



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Staying active is my way of ensuring that I take the fight to Parkinson's and ensuring I am the best me that I can be." - Patrick

It's easy to become discouraged when things like illness, injury, or changes in the weather interrupt your routine. But there are ways to stay motivated when life's challenges get in the way.

- Focus on short-term goals, such as increasing your number of steps each week or how often you go from sitting to standing in a day.
- Reward yourself when you successfully complete an activity, reach a new fitness goal, or when you've done something when you were tempted to give it a miss.
- Keep a diary, write down what you've done
 or use an app to track your progress. Nothing
 beats seeing those active days add up! Why
 not try our sample diary in this guide to get
 you started.
- Find support. When you are active with a friend or family member, you can encourage and motivate each other. You can even just ask someone to 'check in' with you each week and motivate you to keep going.

Keep it up, don't give up!

Nobody said getting (or staying) active would be easy but by now we hope you have the tools and confidence needed for your journey. Don't compare yourself to others, just keep going and remember our key recommendations:

- Some is good, more is better. It's great to be active, but try and do as much as you can as often as you can. And try to get your intensity levels high!
- Keep it enjoyable and varied. If you enjoy
 what you do, then you'll keep doing it. Try
 and vary how you are active. Mix in some
 classes with some gym work, or a swimming
 session with your usual yoga or pilates,
 whatever you enjoy doing.
- Make it social. Being active with old friends or new, or in a class or group, can really increase your enjoyment and motivation. It's also a good excuse for a chat and some cake afterwards!
- Challenge your mind. Keeping your brain as well as your body active can be very beneficial for all of us, and it's especially true for people with Parkinson's.

HOW THE COMMUNITY STAYS MOTIVATED

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I actually believe physical activity has changed my life. It's part of my prescription."



Laurel's never looked back

I was diagnosed with Parkinson's in 2014 aged 57. I was put on medication straight away and had a good response. I also started attending physical activity classes that my local neuro physiotherapist had set up, specifically designed for people with Parkinson's. Since then I've never looked back.

I have found a physical activity plan that suits me. I do Parkinson's specific classes 3 times a week. I also do yoga, pilates and brisk walking. I also combine face-to-face and Zoom classes. It all helps me to work on my core stability, stretching, balance and strength. Sometimes I fall off the wagon and have a duvet day (or two, or three!) But then Parkinson's starts winning again, and I know I must fight it.

I want to continue to be able to walk unaided and retain my balance so I don't fall; to have the strength to do gardening and cleaning and to enjoy leisure activities. I want to look after myself and to help those dear to me for as long as I can. That's my motivation. It will only happen if I take control, keep active and get out of breath every day.

I actually believe physical activity has changed my life. It's part of my prescription. Before diagnosis I was fairly active but it's taken time and effort to be able to keep active at high intensity levels. I've got there and I plan to keep going, to delay progression. It's worth it. Until researchers find a drug to stop the progression of Parkinson's, it's the best weapon. Let's use it!





My advice to anyone wanting to be more active is to look at the good things in life."

John knows an active day is a good day

John is a former Marine AFC player who in 2012 was diagnosed with Parkinson's. He went on to found the walking football and Parkinson's community group, Northern Lights. It's a support network for anyone who needs it and encourages people living with Parkinson's to keep active.

John says, "There are several motivations that help me to keep me active. The first one is my wife. I want to keep well so we can travel and see the world together. I have also got five beautiful grandchildren and I want to see them grow up, and enjoy life with them as much as I can.



Physical activity also helps my mental health. It gives me the feel good factor. On a day that we are playing football, when I am getting my kit together, I know it is going to be a good day.

My advice to anyone wanting to be more active is to look at the good things in life. See the things you can achieve, not the things that you can't. Set yourself small goals, win small battles. That could be climbing up the stairs or walking to the shop. Don't try to conquer the world. Winning small battles against this condition can become infectious."



Knowing the consequences if I were to stop exercising keeps me motivated."

- Janet

More from the Parkinson's community



Ruth Brinkler-Long Chair Parkinson's UK. Peterborough Branch

Ruth sees the benefits of being active at her local group

"Our local group has been attending regular classes for several years in a safe, and enjoyable environment. Classes include Table Tennis, Tai Chi, Walking and Pilates. I have really noticed a positive difference from those who regularly attend. These include improved energy, flexibility, balance and coordination. Being in a social environment has really helped members deal with their symptoms and develop friendships with other group members. There is a real buzz when members get together."



Amelia Khan - mCSP BSc (hons) NHS Physiotherapist

Milly is a physiotherapist and knows that more is more

"All movement is good but if you want to feel the real benefits then you have to get hot and sweaty! The main aim of exercising is to challenge your Parkinson's symptoms, so we are looking for you to do big, powerful and purposeful movements. You don't have to attend a Parkinson's specific exercise class to challenge your symptoms. It can be done with any physical exercise. Aquarobics and spin classes are great low impact, high energy options."



Anna Kharin - Neuro Physiotherapist Laura Douglas - Neuro Physiotherapist

Neuro Heroes are physiotherapists and physical trainers who see the benefit of movement in all their clients.

"For us at Neuro Heroes we believe that physical activity is both medicine and a vital part of life, wherever you are on your Parkinson's journey. If you choose activities you enjoy, you'll train harder, take part consistently and reap the rewards.

We believe that physical activity should be varied and fun to energise and empower you. By getting sweaty and putting in the effort we find people leave sessions feeling invigorated, satisfied and positive."



Further support

There's lots of useful information out there about opportunities to be physically active near you.

- The Parkinson's UK website has an online look up tool to help you find local activities parkinsons.org.uk
- Our YouTube channel has lots of free content to help you be active youtube.com/parkinsonsuk
- The We Are Undefeatable website is a great resource to learn about being active with a health condition We Are Undefeatable supports people living with long-term health conditions, including Parkinson's, to get active in a way that's right for them. For more information about the campaign, visit weareundefeatable.co.uk

- Moving Medicine is a website designed to support people with Parkinson's and their healthcare professionals movingmedicine.ac.uk
- Want to try running for the first time? Try a programme such as NHS Couch to 5K to get you started. Need to get back into the swing of it? Visit parkrun's website to find out where your nearest, weekly 5k takes place parkrun.org.uk

Your local authority's website will also have information about what is on offer in your area.

A huge thank you to everyone in the Parkinson's community who has contributed to this booklet and shared their expertise and experience.

We Are Undefeatable is proud to be working with Parkinson's UK as a charity partner. Together we are passionate about redefining what 'exercise' can look like when living with Parkinson's. We're delighted to be included in this guide, and to show the benefits that getting active can have on your physical and mental wellbeing.

Your weekly physical activity diary example:

Keep track of your activity levels throughout each week and keep old diaries to track progress and share with your healthcare professional.

Week	starting	

Day	Type of activity and amount of effort (include all activities)	Time spent doing each activity (in minutes)	Total number of minutes being active in the day
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone affected by Parkinson's.
Together we'll find a cure.

PARKINSON'SUK

Free confidential helpline **0808 800 0303**Monday to Friday 9am to 6pm, Saturday 10am to 2pm (interpreting available)
NGT relay **18001 0808 800 0303**(for textphone users only)
hello@parkinsons.org.uk
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