

## InTouch Newsletter April 2025

### How Often Should You Change Your Exercise Routine with Parkinson's?

*Neuro physiotherapist Josefa Domingos gives expert advice on when and how often you should change your Parkinson's exercise routine.*

Parkinson's can be an unpredictable and ever-changing condition, so getting your physical activity at a level that works for you can be an ongoing challenge, and leave you asking: "When and how often should you change your exercise routine?"

As an experienced neuro physiotherapist specialising in Parkinson's and other movement disorders, our Josefa Domingos has spent the last two decades helping people with Parkinson's to answer that very question, so we asked her for her expert tips:

#### What reasons are there to change your exercise routine?

"Here are some criteria I suggest people use to assess whether their current exercise routine remains beneficial and if changes are needed:

- **When it is no longer effective for their current health needs or goals.**  
This means that either a) the patient and/or family don't perceive any benefits, b) the person feels bad after exercise, or c) it doesn't help to achieve the person's goal.
- **When it is no longer safe**  
For instance, if a person feels unease during the activities and feels worse afterwards.
- **When they believe they can't do it**  
For instance, because of their skill level or health status.
- **When they stop enjoying it**
- **When it's no longer accessible**  
For reasons like time, location, costs, and how sustainable your routine is.
- **When scientific evidence identifies safety issues with your current choice of exercise"**

## **7 questions to ask yourself before changing your exercise routine**

“The question of how often to change your exercise routine depends on many factors, so I recommend regularly asking yourself the following questions to help ensure that your current activities align with your needs and safety:

**1. Am I enjoying this?**

Does the activity bring you joy, or is it causing stress or discomfort? Exercise should be something you look forward to.

**2. Is it safe for me?**

Consider the safety of the environment, the intensity of the exercise, and whether you're using proper techniques. Is there a risk of falling or injury?

**3. Am I noticing positive changes?**

For instance, are you experiencing improved mood, energy levels, balance, or overall quality of life?

**4. Do I have the right support?**

Support is crucial to maintaining an exercise routine successfully. Do you have a workout buddy, trainer, or group that provides encouragement and assistance when needed?

**5. Is my routine flexible enough to adapt to my needs?**

Can you adjust your exercise schedule or modify activities if your symptoms change or medication timing varies?

**6. Does it align with my health goals?**

Are the activities you're doing helping you reach your fitness or mobility goals, or do you need to adjust your routine?

**7. Am I taking adequate rest and recovery time?**

This is so important. Are you allowing yourself enough time to rest and recover between sessions to avoid overexertion and burnout?

## **What are the criteria for changing from high to low intensity exercise?**

I would use the same questions as I suggested for the need for a change in general (see above).

## **Should people with Parkinson's who want to take up a new sport seek medical advice first?**

Yes, it's highly recommended. All exercise guidelines suggest undergoing a full medical assessment before beginning any new sport or exercise program. This is especially

crucial for people with Parkinson's due to the potential impact of symptoms on physical activity.

If you can't get an assessment immediately, make it a priority to schedule one as soon as possible to ensure that you're taking up the new sport safely and with the right precautions in place.

**Sources:**

Original article by Laura Vickers-Green

[Parkinson's Europe](#)

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## **Communication Tips for Family and Friends if Your Loved One has Parkinson's**

*If your loved one experiences speech and communication problems as part of their Parkinson's, there are ways you can support conversations. Here are some useful strategies to reduce frustrations and help make your conversations more successful.*

1. Make sure you and the person with Parkinson's can see and hear each other. Facing someone with Parkinson's can be particularly important to help them communicate clearly and understand you. You don't need to shout.
2. Be patient. Give the person affected the opportunity to get involved in a conversation but don't pressure them to speak if they don't want to. They may need extra time to respond, so try not to interrupt or walk away.
3. Try to avoid speaking above noise, such as a TV or radio. Try not to be too far away – for example, in another room – when talking.
4. Be reassuring and help them to relax if you can see they're stressed.
5. If you don't understand what they say, ask them to repeat it more loudly and slowly. If it's just a key word you've missed ask them to repeat that word.
6. Try not to pretend you've understood if you haven't.

7. Try not to talk for the person, unless it's absolutely necessary.
8. Avoid finishing their sentences.
9. Don't accidentally ignore the person affected by asking someone to speak for them.

A speech therapist will be able to give you more advice on what you can do to make communication easier. Call the Parkinson's NSW InfoLine for more information on 1800 644 189.

**Source:**

[Parkinson's UK](#)

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## Bone Health and Parkinson's

*People with Parkinson's have a higher risk of fracturing a bone than the general population, so it's especially important to look after your bone health.*

### Key points

- Bone health is important for everyone, but especially if you have Parkinson's.
- You are at more risk of getting osteoporosis when you have Parkinson's, which can weaken bones and make them more likely to break.
- Your healthcare team can assess you and may prescribe medication to help improve your bone health.
- Strength exercises and maintaining a good diet can also help.

### What is bone health?

Bone health really means having 'healthy bones'. Healthy bones are strong enough to prevent fractures, for example when we have a fall. Our bones are more healthy when we have enough calcium in our diet (from milk, and dairy products like cheese) and when we use our arms and legs (such as with exercise).

Both women and men need to make sure that they do the right things to keep their bones healthy.

### **Why is bone health so important if you have Parkinson's?**

Bone health is important for everyone, but especially if you have Parkinson's. This is for lots of reasons.

Osteoporosis is a condition that affects the bones, causing them to become weak and fragile and more likely to break. It's often diagnosed in people with Parkinson's.

The absorption of important nutrients like calcium is reduced if you have Parkinson's. This can result in thinner bones that increases the risk of a fracture.

Loss of balance and falling affects many people with Parkinson's. If your bone health is poor, a fall could lead to a broken bone.

Women are generally more likely to have 'thinner' bones than men, and bones become thinner as we get older. But men who have Parkinson's may also develop thinning bones. So both women and men need to make sure that they do the right things to keep their bones healthy.

### **How does someone know how good their bone health is?**

A number of different factors can help to work out what your risk of poor bone health is. These are combined in a 'risk calculator' that works out your future chance of having a bone fracture (usually over the next 10 years).

Your specialist, Parkinson's nurse or GP can calculate your risk score. The Royal Osteoporosis Society also has a [risk checker you can use](#).

When the risk is high, there are treatments that help to thicken bones and prevent fractures.

When you're at medium risk, you may be sent for a bone scan, also called a DEXA scan. This takes a scan of your bone density and can help decide if any treatment is needed.

When the risk is low, medication is not needed, but you should try to protect your bone health. See below for ways you can do this.

### **What can someone do to look after their bone health?**

If we become inactive our bones get thinner, which increases the risks of having a fracture. Physical activity and exercise is good for bone health, as well as helping you manage your Parkinson's symptoms.

Diet is also very important, particularly calcium. Sources of calcium include milk and dairy products like cheese. Try to aim for 3 servings of milk or dairy foods every day to get the calcium you need.

Vitamin D helps to keep your bones healthy and helps your body absorb calcium. Most of the vitamin D you need comes from the effect of sunlight on your skin but what you eat can also help, especially during the winter. Good sources of vitamin D include oily fish (such as salmon and mackerel), red meat and eggs.

### **Is medication an option if you have poor bone health?**

Medication can improve bone health when the risk of bone fracture is high, or if there is evidence of osteoporosis on a bone density scan.

Supplements like Vitamin D and calcium can help to strengthen bones. If someone is at higher risk, your doctor may also prescribe medication, which can make more calcium enter bones and help make them stronger.

In some people, a mixture of these treatments is helpful. In other people, a supplement is enough to improve bone health.

Like any medication, there are benefits and risks to taking a drug to improve bone health. Speak to your health professional to discuss whether they might be helpful for you to take to prevent or lower the risk of poor bone health.

Sources:

Professor Donald Grosset, Consultant Neurologist

[Parkinson's UK](#)

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## **Choosing the Right Equipment to Help You Get Around**

If your Parkinson's symptoms affect your ability to move around, there is a range of equipment available that you may find helpful. Here are some of the things you should consider to get the right aid for you.

## Choosing a walking stick

### 1. ***What shoes do you usually wear?***

Wear your usual footwear when you choose or adjust your walking stick. If you stand with good upright posture the handle should line up with the bump at the bottom of your wrist bone, with your arm hanging naturally at your side. This will mean that your elbow bends slightly when you hold the handle.

### 2. ***How much upper body strength do you have?***

If your upper body isn't very strong, choose a stick that is light and easy to move forward in time with your stride. You may find the heavier three- or four-footed sticks are more difficult to move forward and may trip you up.

### 3. ***How is your dexterity?***

Choose a handle that is a shape and size that lets you grip it as strongly as you can.

### 4. ***How much do you weigh?***

Walking sticks are tested to a maximum weight, so check that yours is appropriate before buying.

## Choosing a walking frame

### 1. ***Where will you use your walking frame?***

There are different sizes of walking frames. For example, will it fit through doorways when you're at home?

### 2. ***How tall are you?***

Four-wheeled walking frames tend to offer more support than three-wheeled ones because they are wider and are usually made of heavier materials. This makes them good for taller or heavier people. But heavier frames may be more difficult to use, and to lift in and out of cars.

### 3. ***Do you fall often?***

A four-wheeled walking frame, which is heavier, may be more steady if you fall over more often, experience involuntary movements (dyskinesia) or tremor.

### 4. ***Do you experience rigidity or weakness in your hands?***

Sometimes a walking frame may 'get away' from the person using it and cause them to fall. There are different types of brakes available, but make sure they're easy for you to use as some can be difficult if you experience rigidity or weakness in your hands.

## Choosing a wheelchair

1. ***Will you or someone else be regularly putting a wheelchair in a car?***

Look for one that is not heavy to lift, collapses easily and fits into your car or boot space.

2. ***How tall is the person who may be pushing you?***

Make sure handles are at a height that means the person pushing the wheelchair doesn't have to stoop down to reach them.

3. ***Where will you be using your wheelchair?***

Choose a wheelchair to suit the types of areas you will be out and about in. For example, if you'll be on pavements a lot, choose large enough wheels to go over kerbs easily and has anti-tipping features. A lap strap can be helpful, especially when going over kerbs or single steps.

4. ***How is your posture?***

A chest harness may be helpful if you slide out of a chair, or a one-way glide sheet that is designed to limit how easy it is to slide forward.

5. ***Do you experience dyskinesia?***

If so, look for a wheelchair which has sturdy footplates. Plastic footplates can break more easily, or can interfere with the freedom of the front wheels, especially for turns and reversing if they are pushed down.

**Source:**

[Parkinson's UK](http://www.parkinsonsuk.org)

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## Support Group Round-up

*By Stacey Foster, Support Group Coordinator*

Welcome to the March/April Support Group round-up. Before I talk about the Support Group Leaders Conference and Community Symposium, I would like to acknowledge some changes in leadership.

**Northern Rivers (Ballina):** We farewelled and said thank you to Cheryl Beerens after almost 6 years. We welcome Ian Dall, the group's new leader.



**Dubbo:** We farewelled and said thank you to Jim and Barbara Jupp after 6 years. Welcome to Marsha Isbester, their new leader.

**Eurobodalla:** We will farewell and say thank you to Joy Overs, Secretary of the group for 10 years. Joy also travelled to Canberra last year, representing the wider Support Group community, at a Parliament House meeting and reception to mark the formation of the National Parkinson's Alliance.

**Tumut:** We will farewell and say thank you to Barry Whiting after 3 years. Barry established the group and was passionate about raising awareness in the community as well as funds for Parkinson's NSW. Tumut Support Group will continue with participants pitching in to keep it going.

### **Parkinson's Awareness Month**

If you or your support group are involved in an activity or event for Awareness Month, please share it with me so I can put it in the next *InTouch*. Photos and a short summary of what you did, people you spoke to, interesting stories etc would be great to share!

### **Support Group Leaders Conference & Community Symposium**

Across two days in early April, Support Group Leaders travelled to the Sydney Masonic Centre for the first Leaders Conference since 2019 and our Community Symposium. It was a fantastic way to kick off Parkinson's Awareness Month!

There were almost 70 leaders and committee members in attendance, most of them having travelled from regional and rural areas.

It was important for us that the group were collectively recognised and appreciated as volunteers, so the first speaker of the day was Diana Piper from the Centre for Volunteering.

Diana facilitated a great discussion around why people volunteer and what the benefits of volunteering are, whilst acknowledging the challenges. It was wonderful to see the group sharing with one another and realising they have a lot in common with their motivations for volunteering and supporting each other in their shared challenges.

The other aim of the Conference was to build the leadership skills of our Support Group leaders so they can feel confident in running their groups. We invited leadership and management professional, Greg Zimbulis, to speak on 'simple, easy to apply leadership actions to make things happen.'

Greg took our leaders through how to be a more influential and effective leader of their support group; increase participant numbers; increase community awareness and engagement and many other points. He also asked them to answer one important question: "what outcomes would you most like to see change or improve in your group?"

Greg spoke to our leaders about the why, the what, and the how of leadership.

All the leaders in attendance received copies of Diana and Greg's presentations, so if you'd like to hear more, please ask your Support Group leader to share what they've learned and their key takeaways.

John Back, Communications Manager at Parkinson's NSW, and myself also rolled out our Support Group Education Framework which built upon the previous sessions earlier in the day. This Education Framework is all about the day-to-day operations of Support Groups, the nitty gritty.

There was lots of opportunity for leaders to discuss with each other at their tables and then come together as one group at the end. They discussed their own experience with leadership so far, wrote a vision statement for their Support Group, and learned about building a leadership team, succession planning, managing leadership burnout, and Support Group administration – including communications, financial management, annual plans, event management, and risk management. So much information was shared, it was fantastic!

Again, please feel free to ask your Support Group leader for more information.

It wasn't all work! We broke the day up with some fantastic singing ('Let's Get Loud'), led by Kempsey Support Group Leader, Garth Fatnowna on guitar in the morning and afternoon. There were also some physical and mental exercises ('Get Up and Move') led by Inner West Support Group Leader and researcher, Paulo Silva Pelicioni. Thank you to you both for bringing the joy and laughter to the day!

Our CEO, Mary Kay Walker, finished the day with an update on Parkinson's NSW advocacy efforts and our funding submission to the NSW State Government. Mary Kay

emphasised that despite our name having 'NSW' in it, we are not a government organisation, nor is Parkinson's NSW sustainably funded by government.

To back up our work on the funding submission to the state government, Mary Kay has met with more than 30 key officials and gathered over a dozen letters of supports from Members of Parliament to the Minister for Health, over the past few months, urging favourable consideration of our funding submission.

In the evening, we invited our leaders to join us for dinner – a way to say thank you for all the work you do, as well as to unwind after a long day.

The following day was our Community Symposium, where close to 250 people attended (including Support Group Leaders) to hear from Professor Carolyn Sue, Clinical Nurse Consultant Rachael Mackinnon, neurological physiotherapist Dr Melissa McConaghy, speech pathologist Colleen Kerr; Associate Professor Richard Gordon and Dr James Peters. Topics included MRI Guided Focused Ultrasound, exploring medication repurposing in identifying new treatments in Parkinson's, emerging therapies for swallowing, conversation, and facial expression; the impact of exercise on Parkinson's progression, breakthroughs in biomarkers, and being a nurse in Parkinson's research.

Feedback from those in attendance has been that the two days were "worthwhile," "uplifting," "wonderful," "interesting and informative" and a lot was gained from it.

**Thank you to every Support Group leader and leadership team member who attended. I loved seeing all your faces and meeting some of you for the first time. You had to juggle travelling far distances, family commitments, work commitments and health concerns, so you could be there. Thank you.**

Here is a video round up of the Support Group Leaders' Conference 2025

<https://youtu.be/VeJNNIaCR0w>

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**Take 5 - April, 2025**

***A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team (call 1800 644 189).***

**1. Managing Tremors with High-Intensity Movement**

Regular high-intensity exercise can help manage tremors by improving motor control and brain health. Activities like boxing, cycling, and resistance training may reduce symptom severity. Programs like PD Warrior focus on neuroactive exercises specifically for Parkinson's. For tailored advice, contact our InfoLine for a referral to an experienced physiotherapist.

**2. The Impact on Carers – Support Available**

Caring for someone with Parkinson's can be physically and emotionally demanding. Parkinson's NSW offers carer support groups, counselling, and the InfoLine to provide guidance, emotional support, and practical advice. Additionally, Carer Gateway provides access to government-funded support services, including respite care, financial assistance, and coaching for carers. Seeking support can make a significant difference in maintaining well-being.

**3. Early Onset Parkinson's**

Parkinson's isn't just a condition affecting older adults—some people are diagnosed under the age of 50. Early onset Parkinson's can come with unique challenges, including work, family, and financial concerns. Connecting with tailored support through our InfoLine and specialist Movement Disorder Neurologists can help individuals navigate these challenges and access the right resources.

**4. Deep Brain Stimulation (DBS) – When to Consider It**

DBS is an option for some people with Parkinson's when medication alone no longer provides adequate symptom control. It's usually considered for those experiencing significant motor fluctuations or medication side effects. Consultation with a Movement Disorder Neurologist is essential to assess suitability. Parkinson's NSW also runs a DBS & Advanced Therapies Online Support Group, providing a space for those considering or undergoing treatment to connect and share experiences. Contact our InfoLine for more details.

**5. Low Mood and Anxiety – Supporting Mental Well-being**

Many people with Parkinson's experience low mood or anxiety, which can be as challenging as physical symptoms. Exercise, social connection, and diet play a role,

along with medical or psychological support when needed. Read about the 'four happy hormones' and how to boost them on the Parkinson's NSW website.

**For personalised support or more resources on these topics, contact the InfoLine on 1800 644 189. We're here to help!**

**For evidence-based information and advice call the Parkinson's NSW InfoLine  
(02) 8051 1900**

**Parkinson's NSW InfoLine**

Email: [pnsw@parkinsonsnsw.org.au](mailto:pnsw@parkinsonsnsw.org.au)

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