

Parkinson's UK self-management programme

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

What is the Parkinson's UK self-management programme?

Our self-management programme is designed to help you navigate your life with Parkinson's and plan for the future.

The aim is to share experiences and discuss the practical and emotional impact of Parkinson's.

The programme is for people with Parkinson's, partners and carers, and it's available through face-to-face or online groups.



What happens in the groups?

You'll have the opportunity to develop a personal self-management plan covering important things like exercise, relationships, medication and taking care of yourself physically and emotionally.

You'll get printed information about self-management to discuss in your group. Just as importantly, people in the groups also learn from each other's experiences.

Groups are led by trained volunteer facilitators, who are all people living with Parkinson's, and their partners and carers. These volunteers help to create a safe and supportive environment, keep things on track, and lead everyone through discussions, reflection and exercises.

If you want to attend alone, that's absolutely fine – many people do. Equally, it can be very useful for people with Parkinson's and the person closest to them to attend together, take stock and talk about some of the bigger questions of life with Parkinson's.

What do we talk about?

The groups are a discussion and topics include:

- the importance of making connections with others
- looking ahead and at relationships
- focusing on what's important to you
- taking care of yourself physically and emotionally
- planning for the future and developing a personal self-management plan

What are the benefits of taking part?

Self-management means working out and doing what you personally can to take control, live positively and achieve a quality of life that's meaningful for you.

People tell us that as a result of taking part in the groups they feel armed with information and knowledge and more confident, positive, in control and able to move forward. By meeting and talking to others, people also feel less alone.

Participants also gain greater self-awareness and insight.

Who is self-management for?

Our self-management programme can help you whether you're recently diagnosed or you've been living with the condition for some time.

- If you've recently been diagnosed with Parkinson's, you can take some time to think about what that means and what you need to do from here – along with others affected by the condition.
- If you've been diagnosed for longer, perhaps now is a good point to take stock. With any long-term condition it can be useful to do that from time to time, to make sure you're doing all you can to stay well.
- If you've been living with Parkinson's for some time, you may have settled into established ways of managing life with the condition. But it can be useful to revisit that and to hear what others are doing. Your experience may also be just what someone else in the group needs.
- Self-management also works for partners, carers and people in a close supporting role – you are equal members of each self-management group. We want to hear about your experiences and how the diagnosis of a loved one has affected you and your needs.

The programme works best for family and carers who have a significant caring role, such as people who are living with or frequently caring for someone with Parkinson's.

What are the options for taking part?

We offer face-to-face and online self-management groups.

Online groups

Our online self-management groups meet online by live video so everyone can see each other – this makes it feel very much like a face-to-face group. You don't need to be a computer expert and we'll guide you through getting set up.

Groups meet for 6 weeks, with an additional welcome session beforehand.

These groups are great for people who:

- are working during the day (many run in the evening)
- find it difficult to travel
- prefer doing things in the comfort of their own home
- need to be on hand to care for a loved one



Here's what a recent participant said:

“A golden opportunity to communicate with people with Parkinson's and carers on a non-judgemental level. Online gave me the confidence to ask questions or advice – I would not have done that as quickly if I had been face-to-face. I think I built up a relationship with others quicker by doing this online. I felt comfortable in doing this in my own home.”

Face-to-face groups

Our face-to-face self-management groups are a conversation about Parkinson's around a table in a local venue. Groups run for 3 or 6 weeks in different parts of the UK each spring and autumn. Around 12 participants attend, led by two volunteers.

People often describe these groups as welcoming, friendly and supportive. Tea and coffee are on hand and there is usually a fair amount of laughter along the way. People can make new friendships and stay in touch.

How to register for any group

If you're interested in taking part or just want to find out more, please get in touch:

- Visit parkinsons.org.uk/selfmanagement to find out the locations, dates and times of our groups.
- Email us at selfmanagement@parkinsons.org.uk to find out more or express an interest in taking part. If now isn't the right time, you can go on our mailing list to be the first to know about future opportunities.
- Call us on **020 7963 3924** to talk to a self-management programme coordinator.

Here's what some recent participants said:

“It has helped me greatly, mentally and emotionally.”

“Friendly and helpful advice on living with Parkinson's.”

“Gained confidence to speak about my fears.”

“Made me more aware of the need to see myself with needs, rather than being focused on caring for my partner with Parkinson's.”

“Very thought-provoking, leaving me with a sense of a way forward.”

“Great to meet others with the same issues as myself. Good to talk and understand more about Parkinson's. Very worthwhile and I would recommend the programme.”

“The group was very balanced, open and friendly. People felt comfortable in discussion.”

Volunteer to help run groups

We're always looking for people affected by Parkinson's to help run our face-to-face and online groups. You'll be trained and lots of support is available.

If you feel like you are already positively managing things, have experience of talking in similar groups, and have good communication skills, we'd love to hear from you.

Please call us on **020 7963 3924** or email us at selfmanagement@parkinsons.org.uk

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
NGT Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk

