

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

INTRODUCTION TO VOLUNTEERING AS A SELF-MANAGEMENT FACILITATOR



Volunteer self-management facilitators

We need people with Parkinson's, partners and current carers to volunteer as self-management facilitators. You can use your first-hand experience and skills to provide support in your local area.

Overall role:

- The overall role of self-management facilitators is to work together to lead and support a discussion to take place within a group of 12 people.
- To do that it's necessary to closely follow the structure of the facilitators' guide and deliver the content of the programme.
- Using your personal experience, encouraging individuals, keeping to time, and feeding back to the selfmanagement team are all essential.

Time commitment:

- Becoming a facilitator: You will need to take part in some training to become a facilitator. We describe this process on page 6.
- Preparation: In order to facilitate a group, some preparation is needed. Most pairs of facilitators will talk before and after each of the six sessions.
- Facilitating: Our self-management groups happen in spring and autumn. Each group runs over six weeks (2.5 hours per week). With travel, the commitment is up to 12 days per year. Ideally we ask our volunteer facilitators for an initial two-year commitment, but don't be put off if that's not possible.

Here's what some volunteers say they gain from being a facilitator:

"This voluntary work has enabled me to feel more confident again and made me realise that I still have attributes and skills to offer."

"I felt useful and able to use skills that had lain dormant since I retired when I was diagnosed with Parkinson's."

"I learn something that helps me with my Parkinson's every time."

"Seeing the change in the participants as they progress through the course and knowing that you have helped is incredibly rewarding."

"My satisfaction as a facilitator is seeing people come to terms with their change in circumstances in a positive way that allows them to go forward."

Our volunteers share a commitment, drive and energy to support those affected by Parkinson's. As a self-management facilitator you will be join a team making an invaluable difference right across the UK.

What we're looking for and why

People come to the role from a wide range of backgrounds. What they have in common is first-hand experience of Parkinson's, skills in managing groups and a passion for helping others take control, live positively and achieve a quality of life that is meaningful for them.

To be a self-management facilitator we ask that you are a person living with Parkinson's, a partner or current carer. In addition, for this role we are looking for the following experience, skills and qualities:

The experience, skills and qualities we're looking for in this role	Why we think they're important
Experience of positively self-managing your own Parkinson's or a current role as a partner or carer for someone with Parkinson's.	You will find it easier to facilitate if you have some positive and personal experience of exercise, diet, stress-management and emotional wellbeing to offer by way of example.
Experience of talking, interacting and working in similar groups with peers.	We need facilitators to have the confidence in groups that comes from experience. The skill of facilitating is different from teaching or chairing a meeting – it's often less directive.
Experience of handling personal, confidential information.	These groups are an honest conversation about life – confidential and personal things are shared.
Good time-management skills.	Sessions need to start and finish on time.
Good communication skills – including the ability to be heard, to listen and to pick up on what people are saying.	Facilitators need to have a strong enough voice to be heard by everyone. Listening is essential to facilitating any group.
Welcoming, inclusive and non-judgemental about the choices people make.	People are often nervous about joining a group and we want everyone to feel comfortable and able to contribute. Facilitators need to respect other people's decisions and choices.
Able to build relationships and trust through empathy.	Participants need to have trust in the facilitators. By building positive connections, people feel supported and willing to open up and contribute.



“The great thing about facilitation is that you’re not teaching. You have to be able to observe the group and listen to what is being said but also look out for the people who aren’t speaking and give them the opportunity to come in and to express themselves.

“Being a facilitator makes you feel good in yourself because you are helping people to change their lives and the way they manage their condition. I love the buzz it gives me.

Go for it – you will get more out of it than you put in.”

- Sheila

Our self-management programme

Our self-management programme, *A path through Parkinson’s*, is designed to help people affected by Parkinson’s navigate life with the condition.

The programme runs over six consecutive weeks with one 2.5 hour session per week. Each self-management group is run by two people with first-hand experience of Parkinson’s, known as facilitators.

The groups enable 12 people with Parkinson’s, partners and current carers to come together to work out what they, as individuals, can do in order to take control, live positively and achieve a quality of life that is meaningful for them.

Over the six weeks, participants work through a log book – a personal copy of programme content – which they fill in and keep. Facilitators have a detailed facilitators’ guide, specifying each exercise and discussion. Together these two documents give structure and purpose to each session and to the programme overall.

The participants and facilitators sit together around a central table for much of the discussion. There’s also some work in pairs, as well as periods of individual reflection.

What do we talk about?

- 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 a personal self-management plan.

What does it feel like?

For some participants, these conversations are emotional, partly because they look to the future. It can be challenging, but it's a safe and supportive environment because of the structure of the sessions and the role of the facilitators.

The groups are a time to reflect deeply – a shared journey with others living with Parkinson's. Along the way information is given and reassuring tips are shared.

What is the impact of the programme?

People tell us that as a result of taking part, they feel:

- armed with information and knowledge
- more confident, positive, in control and able to move forward
- less alone as a result of meeting others

Participants also say they gain:

- greater self-awareness and insight
- a personal action plan for doing specific things such as exercise, hobbies and therapeutic activities
- improved speech as a result of talking in the group

Here's what some recent participants say they gained from taking part:

"It helped me realise that I am not alone and that there are various stages, degrees and types of Parkinson's. It was very good to talk to other people and hear their stories and ways of coping and living."

"The self-management group focused my attention on what actions to take to make life with Parkinson's better. It has made me more positive about managing my condition."

"I felt I had given myself the right to manage the Parkinson's rather than Parkinson's defining my life."

Feedback from recent groups was very positive:

- 90% of people told us that attending the self-management group helped them to make choices that improved their life in some way.
- 90% of people told us that attending the self-management group made them feel more positive about their current situation.
- 82% of people told us that the self-management programme helped them to better manage day to day life with Parkinson's (as a person with the condition or as a partner or carer).

To find out more visit parkinsons.org.uk/selfmanagement

How to become a volunteer self-management facilitator

Application and training

To help you decide whether to apply, or to receive a copy of the volunteer application form please feel free to contact us on **020 7963 3924** or at **selfmanagement@parkinsons.org.uk**

If you'd like to speak to an existing volunteer self-management facilitator, to hear directly about their experience, we can arrange that.



To apply, you'll need to fill out a written application to tell us more about yourself and how you fit with what we're looking for. If you have any problems completing the form, please contact us and we'll do our best to help.

Once we've received your application we'll arrange a telephone discussion at a mutually convenient time. This usually involves a member of the self-management team and an existing volunteer facilitator. The aim is to talk about your application and answer your questions.

Following the telephone discussion there's time to reflect on whether the role seems right for you. If we all agree that it is, we'll ask you to come along to an initial two-day training course. These days introduce you to the self-management programme and give you the chance to experience parts of it.

Here's what a current volunteer says about the experience:

"Not so very long ago, I was idly browsing through the Parkinson's website when a request for volunteer facilitators caught my eye. I had been retired from work, since I was diagnosed six years ago. I missed the buzz of work and the feeling of self-worth.

The training I received was first rate. I had worked in a number of voluntary organisations over the years and sadly, the training and support there, though well-meaning, was elementary and basic. In contrast, this has been efficient, thought-provoking and highly professional. I have thoroughly enjoyed my training."

- Rosalind

Following the two-day training course there is more time to reflect on the role and decide whether it is right for you. There's then a further one-day session of training and coaching, designed for the two volunteers who will go on to run the group in their area.

Induction and support

If you're new to volunteering with Parkinson's UK, you'll need to complete an online induction to the organisation. You can complete this at home, working at your own pace. It should take no more than two hours.

While running a self-management group, you'll have regular contact with the team and lots of support is available.

Here's what some volunteers say about the support provided:

"The self-management team are great! Human and helpful. You know your contributions are valued."

"The backup from the team at Parkinson's UK is excellent, from the initial training to the first class materials provided."

A member of the self-management team will come and observe one of your first sessions and give feedback. We also invite you to take part in one or more teleconference phone calls with other facilitators from across the UK.

Other information

For this role we ask all applicants to provide details of a referee. This helps to confirm your identity and gives us a picture of your skills and experiences from someone else's perspective.

As a volunteer you can claim out-of-pocket expenses in line with the Parkinson's UK Volunteer Expenses Policy.

Some Parkinson's UK volunteer roles are classed as regulated activities supporting vulnerable people, and volunteers applying for these roles will be asked to undertake a criminal records check. Currently the role of self-management facilitator does not require a criminal records check. However, this position is under review and in the future we may ask volunteers to undergo a check in order to comply with current guidance.

The recruitment process happens over several months and there is lots of support along the way. Reflection is built in and it's fine to decide it's not for you as you learn more. There are many others at parkinsons.org.uk/volunteerroles

Any questions?

If you have any questions, or want more information about the application process, please contact the Parkinson's UK self-management team on **020 7963 3924** or at selfmanagement@parkinsons.org.uk or parkinsons.org.uk/selfmanagement

We look forward to hearing from you.

Every hour, someone in the UK is 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.
Text Relay **18001 0808 800 0303**
(for textphone users only)

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