

An introduction to the Parkinson's UK self-management programme

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Parkinson's UK has been delivering a peer-led self-management programme called *A Path through Parkinson's* since 2013. It was developed in close collaboration with people with the condition.

About the self-management programme

A Path through Parkinson's enables people to share experiences and discuss the practical and emotional impact of the condition. It's made up of six sessions delivered over three or six consecutive weeks and people should attend all as it builds up to a final session of action planning for the future.

It differs from the really valuable support provided by our Branches and local support groups by offering a time-limited, structured and facilitated chance to talk through some of the bigger questions about life with Parkinson's.

Each self-management group is made up of 8-12 people – these can be partners, carers and people who have been living with Parkinson's for varying lengths of time. Self-management groups are free to attend as the cost of the programme is met by Parkinson's UK.

Each of the six sessions has a different theme:

• Session 1: Making connections with others

This helps people connect with others who understand Parkinson's and provides a valuable opportunity to begin to talk about the challenges of living with the condition personally or as a partner or carer.

• Session 2: Looking ahead

This session helps people to start to develop a strategy for looking ahead to help overcome feelings of being stuck or that life has come to a halt.

• Session 3: Looking at relationships

An opportunity to discuss how Parkinson's may change our relationships, the roles we play, the time we spend together and what we talk about.

• Session 4: Focusing on what's important to you

People often find that major life-changing events make them think about what's important. This session is designed to help people identify and focus on these.

• Session 5: Taking care of yourself

A discussion on how to make the most of life now. This could mean taking more care of yourself, thinking about diet, exercise, learning new ways to unwind and have fun – and also being kinder to yourself.

• Session 6: Planning for the future and taking actions

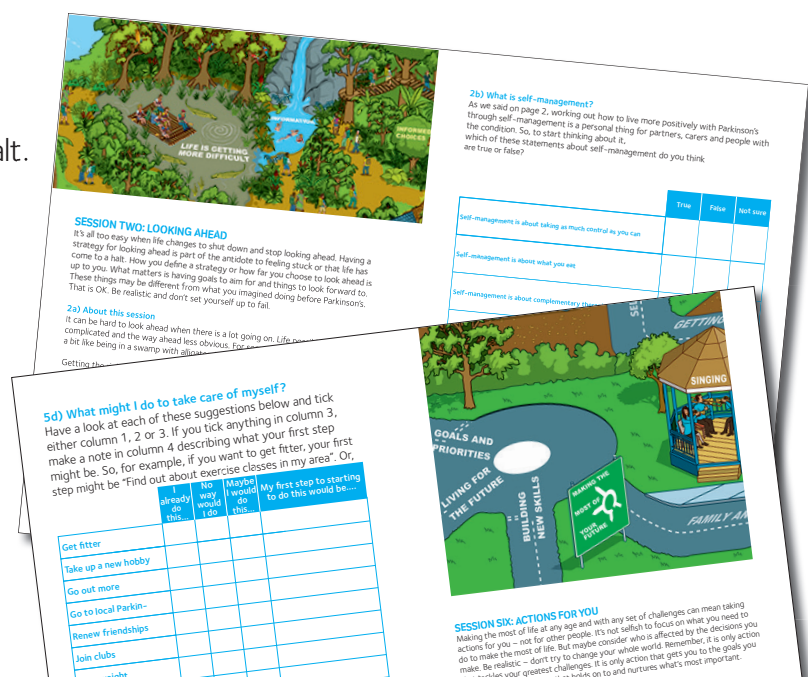
The final session builds on previous discussions to help people identify the actions they can take to make the most of life at any age and with any set of challenges.

About the volunteer self-management facilitators

Each self-management group is facilitated by two people with first-hand personal experience of Parkinson's. All volunteers are carefully recruited, trained and supervised.

Their role is to keep the group moving and checking that everyone is OK with what is being discussed. We don't expect facilitators to have the answers to every question about Parkinson's – that isn't their role. They don't offer advice or information about specific things, such as medication.

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



What difference does the programme make?

Feedback and research shows the following outcomes for people:

- feelings of increased acceptance and the ability to move forward
- feelings of increased confidence, resolve, positivity and control
- feeling more connected and less alone
- feeling armed with information and knowledge
- an understanding of the value of planning and taking action for the future
- feeling able to create a personal action plan for things such as exercise, dance and other therapeutic activities
- greater self-awareness and insight, including into relationships
- improved speech and confidence in talking to others

Where it fits and who it's for

A Path through Parkinson's is a peer-support programme, delivered by people personally affected. It works for people at all stages of the condition.

However, participants do need to be able to concentrate for periods of time and they need to have a strong enough voice to be heard in a group.

It is also a very valuable source of support to partners and current carers who can attend with or without their loved one with Parkinson's.

Our programme focuses on the emotional and practical implications of living with the condition. It complements rather than replicates the very valuable information-based newly-diagnosed or self-management groups run by NHS staff locally.

How people book a place

Groups run in different parts of the UK each spring and autumn. The latest dates and locations are always available at parkinsons.org.uk/selfmanagement.

Anyone interested in attending any of these groups can email selfmanagement@parkinsons.org.uk or call 020 7963 3924. People are welcome to contact us directly or via yourself if they prefer.

Julie: Attended a self-management group in Derby in September 2015

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I'd been diagnosed with Parkinson's for 5 years before joining the self-management group. On the first morning I sat in the car feeling apprehensive, you don't really know what you're going to see, feel or hear.

Talking about Parkinson's has been hard for me for about 3 years, so I was nervous. Within half an hour, I started to relax and realise we're all in the same boat. The people were warm, it was very relaxed. I thought it was absolutely brilliant.

The group helped me to understand there are a lot more people in the same situation as me; sometimes you can feel quite isolated and alone.

I realised that I'm more in control of managing the effects of Parkinson's, and how I live my life, than I thought. People can help and support me but it's up to me to help myself. It's about putting your own life in to perspective and thinking about what you can influence rather than what you can't – and not to get too hung about it when you have a bad day. It helped me think about my work/life balance.

I'm now much more motivated; I've started to do a lot more. I walk the dog more, I watch what I eat... and it's working! I realised I needed to get up and go. ”

