



# A GUIDE TO SETTING UP an activity group



**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.**

# THE BENEFITS OF CREATIVITY

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Many people with Parkinson's find that taking part in a creative activity – such as dancing, painting, photography, singing, theatre and much more – helps to relieve their movement symptoms and improves their quality of life.

Often referred to as a lifeline by class participants, creative activity groups can have very positive effects on wellbeing, self-expression and social integration for people with Parkinson's.

*“Most of us realise that the way we feel emotionally affects the way we feel physically and the reverse is also true. I feel at my best when I am fully immersed in any activity I enjoy and find fulfilling, such as singing, dancing, painting or laughing – something greater than the self.”*

**Bob Taylor, group leader and artist living with Parkinson's**

As well as symptoms affecting movement, speech problems are also common among people with

Parkinson's. But there is promising evidence from research that singing can benefit speech, and more broadly, quality of life.<sup>1</sup>

*“Singing strengthens my voice, so the more I sing the better. I am so glad that I have found this group. I came here on my own and was welcomed at once.”*

**Michael Rawson, Skylarks singing group participant**

A major physiotherapy guideline for Parkinson's recommends dancing to improve mobility and balance.<sup>2</sup> Dance is growing in popularity for people with Parkinson's and there are now a range of dance classes available that aim to boost creative self-expression, fluency of movement and wellbeing.

*“In class, people see you as the person you are, not the person with Parkinson's.”*

**Carroll Forth, English National Ballet Dance for Parkinson's participant**



# SETTING UP AN ACTIVITY GROUP

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Setting up an activity group is a great way for people with Parkinson's in your local area to come together and do something positive and enjoyable. It can be an empowering experience both for the participants and for the teacher facilitating the class – and getting started is more straightforward than you might think.

Various creative classes and groups for people with Parkinson's run throughout the UK, such as dancing, painting, photography, singing, theatre and many more. They are usually open to family, friends and carers too.

Some classes are run by Parkinson's UK local groups and others are run independently.

## What are the first steps?

Before thinking about setting up an activity group, find out what current opportunities for people with Parkinson's already exist in your area. You can find this out on the Parkinson's UK website at [parkinsons.org.uk/support](https://parkinsons.org.uk/support) – simply enter your

postcode in the search box, then look through the list. Click 'Browse all opportunities' to see all the groups that are currently taking place.

You can also get in touch with the Parkinson's UK Local Networks team for guidance and advice. Contact the team on [localnetworks@parkinsons.org.uk](mailto:localnetworks@parkinsons.org.uk) or call **020 7963 3929**.

The next step is to ask around to find out what kind of creative activity people would like to do in your area, and who in your community would be interested in joining your group.

## How do I find a class facilitator?

You may already know someone who you think would be great, or you may need to ask around your networks to find out who people are recommending as class facilitators. You'll need to identify that they are a skilled – and in some cases qualified – class facilitator, depending on what the activity is.





Their personality and ability to make a class fun and engaging is really important – they must have a passion for positively impacting the lives of others and demonstrate excellent communication skills.

When sourcing a facilitator, it's a good idea to request references from previous employers or people they've worked with to gain further insight into their experience. Asking them to show you a demo of how they would deliver a class for people with Parkinson's is a great way to get a feel for whether they're right for your group.

As well as having experience in delivering classes, we recommend that a facilitator needs to have received some training in how to work safely with people with Parkinson's, as well as an understanding of the condition.

There are specialist courses that facilitators can attend to learn about Parkinson's and how to adapt an activity group to the needs of people with the condition. These include:

- People Dancing and the Dance for Parkinson's Network UK: [www.communitydance.org.uk/developing-practice/dance-for-parkinsons](http://www.communitydance.org.uk/developing-practice/dance-for-parkinsons)
- Canterbury Cantata Trust – Caring Through Singing: [www.canterburycantatatrust.org.uk](http://www.canterburycantatatrust.org.uk)

We also recommend visiting our YouTube channel ([www.youtube.com/parkinsonsUK](http://www.youtube.com/parkinsonsUK)) to watch a range of short films about the stories and experiences of people with Parkinson's.

In terms of resources, your facilitator will be able to advise you about any equipment or support they need to deliver the class.

#### **How do I find an appropriate venue?**

Once you've decided what kind of creative activity you are going to be running and you've selected your class facilitator, they may be able to advise you on the right venue.

Or perhaps you already know of a venue that you've worked with in the past. Could they offer you the space in-kind to start with, until you've gathered momentum and the number of participants increases? After that you can negotiate a fair hire fee that's manageable for you.

If you don't have a particular venue in mind, find out if anyone you know has a link with a community centre, organisation or performing arts school. You could also try to find a venue by contacting your council or local charities.

Here are a few things to consider when choosing an appropriate venue that suits your group activity:

- Does the venue have public liability insurance?
- Is the space large enough to accommodate your group, the facilitator and the planned activity?
- Is the venue wheelchair accessible?
- Does the venue have accessible toilets?
- Is there car parking or good public transport links for those who don't drive?
- Are there enough chairs and/or tables for all participants, and are they in good condition?
- Does the venue have any equipment the facilitator will require, such as a sound system, music equipment, etc?
- Are there suitable exits?
- Is there space to serve water, tea, coffee and refreshments?
- Who is responsible for opening and closing the building? It's worth checking this if your class takes place at the start or end of the day, to avoid class participants turning up for a session when the building is locked.
- What's the floor surface like? Carpeted floors are not really suitable for movement classes, but a floor that's too slippery presents a potential risk. If in doubt, ask your class facilitator.

It's a good idea to allocate some time at the end of the class for refreshments and socialising, to make the activity into a social occasion.

This has been proven to have wonderful benefits for the participants' experience of the class and can enhance overall wellbeing.

## Funding

You'll need to work out how to fund your group activity. Do you need to put funding in place or are you able to self-fund your classes?

Consider what costs you'll need to cover, such as:

- venue hire
- paying the facilitator
- any volunteer expenses
- purchasing necessary equipment
- PPL and/or PRS licenses for using music
- printing necessary worksheets
- supplying refreshments before or after the class

Here are some examples of funding bodies you could approach:

- Awards for All, Arts Council England: [www.biglotteryfund.org.uk/global-content/programmes/england/awards-for-all-england](http://www.biglotteryfund.org.uk/global-content/programmes/england/awards-for-all-england)
- Paul Hamlyn Foundation: [www.phf.org.uk](http://www.phf.org.uk)
- Sainsbury Family Charitable Trusts/Headley Trust: [www.sfct.org.uk/the-headley-trust](http://www.sfct.org.uk/the-headley-trust)

## Should I charge for the class?

If you are setting up a class that involves a specialist facilitator, it is likely that both class fees and some funding may be required in order to offer a sustainable activity.

As a starting point, look at other similar classes in the area and compare costs. Some organisers charge for their classes and some don't. There's no right or wrong choice – it all depends on the level of costs you need to cover.

Charging a small entry fee has some benefits:

- It enables you to cover costs.
- You're able to monitor the number of spaces in the class in relation to the venue capacity.
- When people have paid for an activity they're more likely to commit to attending.

The average cost of a class tends to be around £3 to £7, depending on the circumstances.

On the other hand, there are benefits to free entry as well: it promotes accessibility and saves costs for the participants.

### How often should the class take place?

It's totally up to you how often the classes take place and this may depend on your budget and/or time constraints. Popular options include weekly, twice a week, every other week or monthly.

Some organisers plan their classes in term time so there are no classes during the school holidays – this can be a nice advantage for those with children or grandchildren.

### How long should each class last?

This depends on the activity, as each creative class will be different with various requirements. An average class length is one hour to one and a half hours. Make sure you allocate some time at the end of the class for refreshments and socialising.

### How do I ensure each class is managed effectively?

Have a think about who will be responsible for the day to day management of the class and being the main point of contact for people interested in signing up. This includes:

- the sign-up process
- ensuring a data protection process for everyone who signs up
- registration at each class
- organising each session
- sourcing and managing any volunteers
- managing the relationship with the venue
- liaising with the facilitator
- sourcing any refreshments for the class
- setting up and taking down the space

This is quite a big commitment, so you may want to ask some volunteers to help with certain aspects of the management.



## Should I recruit volunteers to support my class?

Whether you'll need the support of volunteers really depends on the nature of the activity you're delivering and the class size. For example, in a dance or exercise-based class, volunteers could help with signing up participants, preparing the room for the class and offering encouragement on the day.

If you do require volunteers, think carefully about their role to make sure it will be as fulfilling for them as possible and put together a role description to clearly list their tasks.

To recruit your volunteers you could take a look within your professional network to see who would be able to commit to supporting your classes – perhaps someone who already runs or assists classes of this nature and has experience of working with people with neurological conditions. Students who are studying creative intervention or healthcare for people with neurological conditions might benefit from gaining work experience in this area.

If you're thinking of including volunteers in your activity group, we highly recommend using our award-winning Parkinson's UK online volunteer induction to ensure the volunteers feel confident and supported when starting their role:

**[parkinsons.org.uk/module1](http://parkinsons.org.uk/module1)**

For further advice and guidance about recruiting volunteers, contact your local volunteer centre.

## What safety considerations do I need to take into account?

Ensuring everyone's safety is very important during any activity. Before starting your group, ensure that your facilitator has an opportunity to see and assess the space where you plan to hold your sessions, so they can plan accordingly.

It's advisable for you and the class facilitator to conduct a risk assessment of the venue to make sure the space is suitable for your activity, and to ensure all health and safety precautions have been taken into consideration.

## What insurance do I need to consider?

Ask your class facilitator to confirm that they have their own public liability insurance to cover the activity you are asking them to do. No activities should take place unless the facilitator has insurance to cover the activity.

You or your facilitator can find further information about appropriate insurance by contacting the governing body of their activity. For example, People Dancing (**[www.communitydance.org.uk](http://www.communitydance.org.uk)**) has an insurance scheme for dance and movement activity.

## Do I need to ask for filming and photography consent?

If you plan to film or photograph any of your classes, you'll need to ensure all your participants consent to this. You'll also need to be clear about how you plan to use the footage and imagery. You can find basic consent form templates for this online. If any participants do not wish to be included in any filming or photography, you can arrange the room to ensure they will not be included in the shots.

## How do I market my activity group?

It's important to spend some time marketing your activity group to give yourself the best chance to reach people with Parkinson's and their family, friends and carers.

Marketing is more than just advertising, selling and promotions – it's the whole process of knowing who you're trying to reach, figuring out the right message and action for them, and telling them in the best possible way.

## Here are some ways to encourage people to join your class and experience what you have to offer:

- Deliver a free taster class by an experienced facilitator to draw people in.
- Offer a meet-up, discussion or question and answer session about the group, so people can find out more before they come along for a class.
- Advertise that people can bring along a carer, partner, friend or family member for support. Offering a 2 for 1 deal is one way to help everyone feel welcome. (For information about whether to charge for your classes, see page 5).



### And here are some suggestions about how to promote your group:

- Arrange a launch event for your activity group, and invite friends and family along who can help spread the word. This will help raise the profile of your group and show local decision makers that there is an active Parkinson's group in the local area.
- Contact your local newspaper about including an editorial piece about your group. When writing the article, think about the back story – how did you get to this point of starting up a group? What inspired you? What would you like to raise awareness of? What benefits of creativity for people with Parkinson's can you share with the journalist? Any photos you have of the class will also be a strong addition to the article.
- Promote your group on your social media channels – you never know who will see the post and have a connection to Parkinson's, or know people who they can forward the information on to. You could also create a Facebook group for your class so people can receive updates about class information.
- Produce some flyers, leaflets or posters that

show all the details – such as the time, location, parking and transport options, what to wear and what to expect and so on – and hand them out at local community centres, organisations and performing arts schools to spread the word.

- Invite your local Parkinson's nurse, speech therapist, physiotherapist, occupational therapist and even your local politician along to a class. They can signpost your group to other people.
- Ask your nearest Parkinson's UK local group to tell their members about the class and include details in their newsletter.
- Tell us about your activity group so we can list it for you on the Support for you area of our website. Contact us at **activities@parkinsons.org.uk**

### Should I get feedback from my participants?

Yes! This is very important to ensure longevity for your activity group. By receiving feedback from your participants, you'll get an insight into what they enjoy doing the most, their impression of how the class is run and any suggestions for developing the class. This can be a quick, short survey you provide them with every few months.

## Summary checklist

- Find out current opportunities for people with Parkinson's in your area on the Parkinson's UK website at [parkinsons.org.uk/support](http://parkinsons.org.uk/support)
- Identify a skilled class facilitator who has a passion for positively impacting the lives of others.
- Select an appropriate venue for your activity group.
- Get in touch with the Parkinson's UK Local Networks team for information and advice and to find out how we can support you.
- Before starting your group, ensure your facilitator has an opportunity to assess the venue, so they can plan accordingly.
- Ensure your class facilitator and the venue have their own public liability insurance to cover the activity.
- Look to your network to see who can help you bring people together to support the delivery of your group.
- Think about ways can you encourage people to try out your class and experience what you have to offer.
- Promote your group!
- Ask for feedback.

### Any questions?

If you have any questions, please just get in touch on [marketing@parkinsons.org.uk](mailto:marketing@parkinsons.org.uk) or **0800 652 8978**.

Thank you to everyone who contributed to and reviewed this guide:

**Grenville Hancox, Trish Vella-Burrows, Roger Clayton, Kiki Gale, Sophia Hulbert, Bob Taylor and Philip Bungay.**



## References

1. Stegemöller EL, Radig H, Hibbing P, et al. Effects of singing on voice, respiratory control and quality of life in persons with Parkinson's disease. *Disability & Rehabilitation* 2017;39(6):594-600.
2. Keus S, Munneke M, Graziano M, et al. European physiotherapy guideline for Parkinson's disease. 2014.

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.**

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Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm,  
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(for textphone users only)

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