PARKINSON'S UK

CHANGE ATTITUDES. FIND A CURE. JOIN US.

LOCAL GROUP DIRECTORY


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WELCOME TO YOUR UPDATED LOCAL GROUP DIRECTORY

Hello

This directory has been revised to include the latest information as of summer 2015 and to help everyone offer the best possible local support to people living with Parkinson's.

It's designed to be your 'one stop' guide to essentials such as legal and financial matters or health and safety requirements. There's also up-to-date information on things like fundraising, campaigning and research as well as details of Parkinson's UK policies.

Remember we are always here to help and can offer you a great deal of advice and practical support. The teams at the UK office have a wide range of experience and expertise you can call on – so please do make the most of them. You'll find an updated contacts list on **page 10**.

The support we offer locally is the backbone of Parkinson's UK and the work of the charity simply wouldn't happen without your contribution. I hope this directory will make your valuable work easier and help you to provide that support as smoothly as possible.

Working together, we really can achieve our goal: to find a cure and improve life for everyone affected by Parkinson's.

Thank you for everything you do to support this.

With best wishes

Tyna Brych
Head of Local Networks

LOCAL GROUP DIRECTORY

1. Introduction

2. Running your Local Group

3. Local Group Activities

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5. Talking about Parkinson's UK


HELLO
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PARKINSON'S CHANGE ATTITUDES. FIND A CURE. JOIN US.
Hello Kitty
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1.

INTRODUCTION


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1A. WHO IS THIS DIRECTORY FOR?

This directory is for the local groups of Parkinson's UK.

It's a guide to help you give the best possible support to people living with Parkinson's in your community.

It tells you where to get the help and information you may need, including contact details of teams at our UK Office.

This directory has been revised to reflect our new ambition for 2020. We want everyone, everywhere to have access to the support that people with Parkinson's have told us they want to see locally. Please read section **1C** and find out more.

What you need to know

When you see the term **'local group'** in this directory, it means both branches and support groups.

The **Local Group Rules**, revised by the Board of Trustees in 2015, explain what local groups **must** do.

The **Local Group Directory**, explains how to run local groups and who to contact for support or more information.

Where the words "should", "may" or "it is good practice" are used, local groups are **recommended** to use this as the **best approach**.

The directory signposts to forms and templates available on the Parkinson's UK website, **parkinsons.org.uk**.

If you don't have access to the website, please contact the Local Networks team for a copy.

1B WHO TO CONTACT

Here are the contact details of the teams at the Parkinson's UK office who can help you carry out your vital work.

Governance (and Data Protection Officer)
020 7932 1327
governance@parkinsons.org.uk

Local Networks Team
020 7963 3929
groupnetwork@parkinsons.org.uk

Local Networks Finance Team
020 7932 1324
treasurers@parkinsons.org.uk

Supporter Services Team
020 7932 1344
membership@parkinsons.org.uk

Volunteering Team
020 7963 9328
volunteering@parkinsons.org.uk

Advisory Services Helpline
0808 800 0303

Creative Arts
020 7963 3923
creativearts@parkinsons.org.uk

Facilities Team
020 7931 8080
facilities@parkinsons.org.uk

Marketing Team
0800 652 8978
marketing@parkinsons.org.uk

Resources
0845 121 2354
resources@parkinsons.org.uk

Media and PR
020 7963 9370
pr@parkinsons.org.uk

Digital Team
020 7963 3919
web@parkinsons.org.uk

Policy and Campaigns Team
020 7963 9349
campaigns@parkinsons.org.uk

Regional Fundraising Team
020 7963 3912
fundraising@parkinsons.org.uk

Research Team
020 7963 9398
rsn@parkinsons.org.uk

Celebrity Team
020 7963 9303
celebrity@parkinsons.org.uk

Parkinson’s UK Website
parkinsons.org.uk

UK Office
215 Vauxhall Bridge Road, London, SW1V 1EJ
020 7931 8080

1C. PARKINSON'S LINKS

For everyone, everywhere

In 2014 we started to think and talk about what should be available locally for people affected by Parkinson's and how it can best be provided . Our starting point was to ask people affected by Parkinson's what they needed. They identified a number of different support and activities that are fundamental to them being and staying "in control" of Parkinson's.

Parkinson's UK is committed to helping people find the information, support and services they need – whenever and wherever they need them. This is what we call **Parkinson's Links**.

We may signpost people to activities and services, we may work in partnership with another organisation, or it might be a service or activity that we deliver ourselves through staff or volunteers. In every case, we will encourage people to make the connections they want to make, in the most convenient ways for them, and we will support them to do this.

Parkinson's Links support and activities

The table opposite lists the support that people affected by Parkinson's have told us they want to see in their local area. Together these make up the core components of Parkinson's Links. To ensure that we use charity money in the most effective way, we have also agreed who should benefit from this support. This is also shown opposite:

	Who these are for?		
	People with Parkinson's	Carers	Others
Mutual support, ie the opportunity to share experiences with people in a similar situation	✓	✓	
Information, advice and signposting to further help	✓	✓	✓
Befriending	✓	✓	
Exercise	✓	✓	
Therapeutic activity	✓	✓	
Self-management	✓	✓	
Social activity	✓	✓	✓
Financial assistance (local grant funding)	✓	✓	
Listening to views, feedback and needs	✓	✓	✓

People also said that they expect there to be a number of different activities happening in their local area:

- campaigning
- access to information about, and opportunities to participate in, current research projects
- marketing activity
- fundraising

Parkinson's Links and local groups

Parkinson's UK staff, local groups, local volunteers and other organisations are all part of providing access to **Parkinson's Links**.

Local groups are already an important part of enabling access to Parkinson's Links through:

- providing friendship, support and activities that people affected by Parkinson's have told us they need to stay in control
- working in partnership with other organisations to provide this support
- signposting people affected by Parkinson's to information, support and services available

Helping people to access Parkinson's Links

We know that currently not everyone across the UK is able to find the information, support and services that they need, so we will work together – staff, local groups and volunteers – to make sure that we are providing access to **Parkinson's Links** for everyone affected by Parkinson's locally.

We've listened to what you've told us and we know that some groups are eager to do more while others don't have capacity. We do not expect our current local group network volunteers to take on any additional work or responsibility unless they want to, and we will work together locally to decide the best way to make **Parkinson's Links** available.

The Board of Trustees has agreed that our priority now is to focus on providing access to **Parkinson's Links** locally. This means that there may need to be changes to some activities or services provided by local groups, so that we can focus on delivering **Parkinson's Links**. Local staff will work with you to agree the best way to do this. This will build on the great things that local groups are doing and support all of our volunteers to do what they want to do.

There are likely to be some gaps between our ambition to make **Parkinson's Links** available and what people currently have access to. We will work with local groups and volunteers to see how we can best fill these gaps, and to develop tools and resources to support access to **Parkinson's Links** across the UK.

The guidance in the Local Group Directory and Local Group Rules 2015 are the framework to be used to run your local group and plan all support and activities.

1D. LEGAL STATUS

The Parkinson's Disease Society of the United Kingdom was founded in 1969 by Mali Jenkins, whose sister had Parkinson's. The Society rebranded in 2010 and since then we have operated under our trading name "Parkinson's UK".

Parkinson's UK is an incorporated charity. This means it is not only regulated as a charity by the Charity Commission (registered in England & Wales – No. 258197) and the Office of the Scottish Regulator (registered in Scotland – SC037554), but is also a registered company limited by guarantee and registered at Companies House (registered in England & Wales – No. 00948776). The charity is therefore subject to both charity and company law.

As an incorporated charity, Parkinson's UK is recognised as a separate legal entity distinct from its members and Trustees. This protects Trustees from personal liability and allows the charity to act in its own name.

Because it is also a company limited by guarantee, members have an individual financial liability to the charity. However this is limited to a sum not exceeding £1 and is only payable in the event that the charity is wound up.

The charity's governing document, its Articles of Association (the Articles), set out the regulations for its internal management. The Articles were reviewed in the spring of 2014 and are the new Articles adopted at the 2014 AGM. Copies of the Articles are available from the Company Secretary.

Board of Trustees

The Board of Trustees (the Board) is responsible for the overall governance and work of the charity. As we are an incorporated charity, members of the Board are both Trustees of the registered charity and also Directors of the registered company.

All our Trustees are volunteers and do not receive any remuneration for their services, but may claim reasonable expenses incurred through attending meetings or through other duties.

The Board usually meets six times each year. It is responsible for directing the affairs of the charity and ensuring that it is solvent, well run and delivers charitable outcomes for the benefit of people affected by Parkinson's.

The Board is made up of seven elected Trustees (four from England and one from each of Northern Ireland, Scotland and Wales), five appointed Trustees and up to three co-opted Trustees.

Trustee recruitment is managed by the Nominations Panel (a committee of the Board, further details below) with the aim of ensuring that there is a good mix of skills on the Board and that succession planning needs are met. Our Trustees have a broad range of skills and expertise and many have personal experience of Parkinson's, either personally or through family and friends. Details of our Trustees can be found on our website: **parkinsons.org.uk/trustees**

Committees of the Board of Trustees

The Board has delegated certain responsibilities and decision making to a number of committees established to support its work. The role and remit of each committee is set out in written terms of reference and includes details of any authority delegated to it as set out in the charity's delegated authority policy.

The minutes of all committee meetings are made available to Trustees. Each committee is required to submit an annual written report to the Board summarising its activities and the use of any delegation.

Executive Committee

The Executive Committee meets as required and can act on behalf of the Board in respect of any matter which is required urgently. The Executive Committee also meets annually to appraise the performance of the Chief Executive.

Audit Committee

The Audit Committee usually meets three times a year to assist the Board in ensuring that the charity has effective internal control and risk management systems in place and is operating within approved policies.

Investment Committee

The Investment Committee usually meets twice a year and is responsible for reviewing and monitoring the performance of the charity's investment portfolio.

Nominations Panel

The Nominations Panel usually meets four times a year and is responsible for reviewing the charity's recruitment procedures to ensure they remain effective. The Panel also makes recommendations for appointments and co-options to the Board to ensure that the board has the full range of skills and expertise required to operate effectively.

Country Councils

The Country Councils of Parkinson's UK falls under the governance and constitution of the charity and are not separate legal entities, nor are they autonomous. However, the Board delegates certain responsibilities to their committees through rules and guidelines.

Parkinson’s UK Sales Limited

The charity owns the entire share capital of Parkinson’s UK Sales Limited, a company limited by guarantee and regulated by Companies House (registered in England and Wales, 1575175).

The company’s activities include the trading element of fundraising events and the sale of Christmas cards, stationery and general gift items. The Board of Directors of Parkinson’s UK Sales usually meets once a year and is responsible for the overall governance and work of the trading company. The company annually donates all its profits to Parkinson’s UK.

More information

For more information about the governance of the charity please contact the Company Secretary.

Email: **governance@parkinsons.org.uk**
Telephone: **020 7932 1327**
Post: Company Secretary, 215 Vauxhall Bridge Road, London SW1V 1EJ

1E. LOCAL GROUPS AT PARKINSON'S UK

We're the UK's leading Parkinson's support and research charity.

Our vision – our ultimate ambition – is to find a cure and improve life for everyone affected by the condition.

Local groups are vital to the work of the charity, helping to ensure we reach people who need our help in every area of the UK. Run by volunteers and supported by local staff teams, they offer friendship and support to everyone affected by Parkinson's.

Local groups vary in size and structure. We distinguish between branches and support groups, but refer to them collectively as local groups.

Anyone affected by Parkinson's can benefit from all of our services – whether or not they are members of a local group or of Parkinson's UK. People who are interested in Parkinson's UK membership can join online by visiting our website **parkinsons.org.uk**, or by calling the Supporter Services team at UK Office on **020 7932 1344**. Local groups can also order membership forms from City Digital Limited by calling **0845 121 2354**.

How we work together

Local groups are not independent organisations and are not autonomous, but are an integral part of Parkinson's UK. Local groups share the organisation's charity number and their accounts are consolidated as part of Parkinson's UK annual accounts.

Our Board of Trustees (the Board) is legally responsible for the finances and activities of Parkinson's UK, including those of local groups. To help local groups carry out their vital work in a consistent and appropriate way, the Board has developed the following framework:

- the Local Group Rules
- the Local Group Directory
- the policies and procedures of Parkinson's UK

All local groups must work within this framework. This is essential to ensure the Board can fulfil their legal responsibilities and safeguard the services and activities delivered locally for the benefit of people affected by Parkinson's.

1F. WORKING TOGETHER

Parkinson's UK is committed to encouraging a safe and supportive environment for all our volunteers and staff. This can only happen when everyone is committed to working together effectively and collaboratively and in the spirit of our values. We therefore ask that everyone agrees to and adopts the following.

Our Values	Behaviours that come from our values. We will:
We listen Everything we do is based on the experiences of people affected by Parkinson's	• Keep it professional at all times. • Make sure that everyone has their say. • Not interrupt when others are talking. • Listen and hear what is being said. • Accept agreed ways forward in good faith.
We unite We bring everyone together behind one shared vision	• Seek the win-win compromise and accept and embrace change. • Work together in the face of change for the good of all with Parkinson's, always working with the bigger picture in mind. • Realise that there will be occasions where our personal views may be different than the majority and accept other's views graciously. • Respect individuals as colleagues and human beings, recognising their roles and responsibilities and showing empathy for the situation of others.
We inspire Our energy and determination inspire those around us	• Respect different and diverse views. • Find different ways to look at things. • Encourage and empower each other. • Support and motivate each other.
We innovate We are forward thinking, always seeing to improve	• Share experiences – come up with new or better ways of doing things from a positive position and not overly focus on our own situation.
We're inclusive We reach out to the whole Parkinson's community	• Respect and welcome people from all ages backgrounds and abilities. • Ensure everyone affected by Parkinson's can access all support and activities.
We focus We deliver results and make the most of our resources	• Work together in partnership to ensure that we serve people affected by Parkinson's in the most efficient and effective way. • Respect and appreciate the skills and responsibilities of individuals.

To further ensure that our volunteers have a positive experience, Parkinson's UK will also:

- ensure volunteers have a good understanding of Parkinson's UK
- provide volunteers with full information about their role
- ensure volunteers have access to an induction, training, development and support throughout their volunteering
- provide safe volunteering conditions and ensure volunteers are covered by adequate insurance
- provide volunteers with the opportunity to share their views and opinions on the organisation and its work
- consult volunteers on matters related to volunteering
- ensure volunteers are recognised and valued

This information is from 'Volunteering Policy: Our Commitment to Volunteering'. For a copy please visit **parkinsons.org.uk/localgroupresources** contact the Volunteering team by emailing **volunteering@parkinsons.org.uk** or calling **020 7963 9328**.


PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.
GAME
START HERE
Brand new maps out now
1200 Microsoft points only 99p
Trade-in
MODERN WARFARE
enjoy the rewards

2.

RUNNING YOUR LOCAL GROUP

2A. RECRUITING AND SUPPORTING VOLUNTEERS

Volunteers are the most precious resource in local groups so we must make the most of their generous support. It's vital your local group finds people with the right skills for volunteer roles, and gives them the help they need to achieve your group's goals.

Volunteers are supported locally by the local staff team. There's also a small **Volunteering team** at UK office who are responsible for ensuring that volunteers across Parkinson's UK are well supported and able to make a positive contribution to achieving the charity's goals.

All volunteer opportunities are advertised on the Parkinson's UK website at **parkinsons.org.uk/volunteerroles**.

Recruitment

The first stage of recruiting a volunteer is to think about what you need someone to do. If you are a branch, there may be a vacant role on the committee that needs to be filled. Your group might have other needs, such as volunteers to help with refreshments or to organise specific activities such as a singing group.

When you have identified what volunteers are needed, your Volunteer Coordinator will be able to provide the relevant role description (or in unusual cases, help you to write and risk assess a new one). They can help you to advertise the role and manage the selection process to make sure that the role is right for the volunteer.

There is a standard application form for all volunteers. Please ask all new volunteers to complete the form and return it to the **Volunteering team**. This enables us to keep our database up-to-date, keep in touch with volunteers and evaluate their work. Accurate information is important for lots of reasons, including helping the charity to secure future funding for our work. The **Volunteering team** will follow up references for volunteers taking on some volunteer roles, including Officers on Branch Committees and Support Group Co-ordinators and Finance Contacts.

If the volunteer role is on a branch committee, candidates will need to be elected at the next AGM.

If unsuccessful applicants for roles are still interested in supporting the charity, the **Volunteering team** will try to help them to find another role.

Support and training

When a volunteer is first recruited, the Volunteer Coordinator will provide a short induction to the charity and the volunteer's role. This includes sharing relevant policies, including the Volunteer Policy, Volunteer Expenses Policy, the Health and Safety statement, and information about insurance. This will include completing the online induction modules at **parkinsons.org.uk** (provided in paper format for volunteers without access to a computer). After the induction, most support for volunteers will come from within the group. Some volunteers will be invited to local forums and other appropriate learning and development activities for their role. The Volunteering team are working on improving learning and development opportunities for volunteers. If you have identified particular training needs for volunteers in your group please contact the **Volunteering team** at **volunteering@parkinsons.org.uk** or on **020 7963 9328** to pass on your ideas.

Groups should only pay for training if it has been agreed with local staff to be necessary for volunteers to carry out a specific role. Paying for training that is not directly related to the role could be considered a taxable benefit by HMRC.

Problem-solving

Occasionally problems arise within groups. These can often be solved informally within the group or with a small amount of help from the Volunteer Coordinator. If the problem is more serious, or a volunteer is in a role that's not right for them, you may need to use the Volunteer Problem-Solving Policy.

Moving on

When the time is right, volunteers may choose to step down from their roles. Parkinson's UK is keen to gather feedback from volunteers and a Moving On form is available to be returned to the Volunteering team.

2B. LOCAL GROUP VOLUNTEERS

Local groups are not independent organisations. They are an integral part of Parkinson's UK. The Board of Trustees are responsible for the activities of Parkinson's UK and therefore also for local groups.

This means volunteers responsible for the running of local groups are accountable to the Board of Trustees. They must ensure all activities undertaken by local groups are compatible with our aims and objectives as set out in the Local Group Rules and delivered in accordance with the guidance in this directory.

Local groups are supported locally by staff and also by a team at the UK Office. This team is responsible for ensuring that local groups and staff across Parkinson's UK have the help they need to make a positive contribution to achieving the charity's goals.

What is the difference between a branch and a support group?

Branches are run by a management committee that must consist of the following specific roles: Chair, Treasurer and Secretary. All volunteers of the management committee must be elected according to the process set out in the Local Group Rules 2015.

Support groups are run by a Support Group Coordinator and Finance Contact. There is no formal election process for support groups. However there is a structured volunteer recruitment process which your Volunteer Coordinator can help you with.

Local groups must not hold more than one year's worth of local expenditure as reserves. Any remaining funds must be forwarded to the UK Office to support centrally funded activities in accordance with the Financial Framework. Support groups have a £2,000 limit on funds that can be held in their bank account – anything over this limit is held on behalf of the group at the UK Office.

Local group volunteer roles

It is important that volunteers are only recruited if their skills and experience match those outlined in the volunteer role descriptions. This is to help ensure they will fulfil their roles effectively and get the most out of their volunteering experience.

All volunteer roles must have a role description clearly outlining what the role entails. Role descriptions are available from your local staff team or from the Local Networks or Volunteering teams at UK Office.

The table below shows the standard volunteer roles associated with local groups. **Some local groups may have additional volunteer roles to those listed here, or may not have all of them**.

Volunteer Roles	Branch	Support Group
Chair	✓	✗
Vice chair	✓	✗
Treasurer/Finance Contact	✓	✓
Secretary	✓	✗
Social secretary	✓	✗
Membership secretary	✓	✗
General committee	✓	✗
General non-committee	✓	✗
Coordinator	✗	✓
Helper	✗	✓

Some branches have a Branch President. The role of Branch President is to act as an ambassador for Parkinson's UK and, in particular, to support local group initiatives aimed at influencing key policy makers and maintain effective support from the media to raise awareness of Parkinson's locally. If you are considering approaching a local celebrity, please follow the guidance on working with celebrity supporters in section **5G**.

There are also other volunteering opportunities locally. For more information please contact the **Volunteering team** on **020 7963 9328** or **volunteering@parkinsons.org.uk**.


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3.

LOCAL GROUP ACTIVITIES

3A. LOCAL GROUP SERVICES AND ACTIVITIES

Who they are for

As a charity we are here to support people living with and affected by Parkinson's. Our vision – our ultimate ambition – is to find a cure and improve life for everyone affected by Parkinson's. All local group activity must be directed towards achieving this vision. Activities that are not in pursuit of this vision can put the charity at risk and should not be undertaken. So it is vital that our funds are primarily used to provide services and support people affected by Parkinson's. While it's OK for other people to join in, our focus – and money – should be on people directly affected by Parkinson's.

This also means that anyone affected by Parkinson's can benefit from all of our services – whether or not they are members of a local group or of Parkinson's UK.

Services local groups can provide

Here are some examples of services that local groups may organise, provided they are for the benefit of people directly affected by Parkinson's.

Transport

Some people with Parkinson's may struggle to get to meetings or activities if they can no longer drive or use public transport. Local groups can offer a taxi or community transport service, subsidised or fully paid for out of group funds. This can enable a wider range of people to access the activities and support the group provides.

In 2014 we developed resources to enable groups to set up their own transport services, recruiting Volunteer Drivers to give people lifts to group activities and meetings, with Volunteer mileage expenses reimbursed from group funds. Any new driving service must be set up using these resources. If your group is interested in setting up a driving service please contact **volunteering@parkinsons.org.uk** or call the Volunteering team on **020 7963 9328** for more information.

Individuals sometimes offer lifts to friends or acquaintances informally. If people in your group do this, please be clear that the arrangement is personal and not a service provided by Parkinson's UK. Expenses must not be reimbursed to people giving lifts to meetings in a personal capacity from local group funds.

Information, advice and support to people living with Parkinson’s

Local groups have excellent knowledge and experience of local services and support for people affected by Parkinson’s. This is exactly the sort of information that can be really helpful to people at any stage of life with Parkinson’s.

However it’s really important that anyone providing information and advice has the most up-to-date knowledge and information about all aspects of living with Parkinson’s. For this reason, the best approach is to refer people requiring one-to-one information and support to the following services provided by the charity:

- advisory services helpline – **0808 800 0303**
- the Parkinson’s UK website **parkinsons.org.uk**
- Parkinson’s Local Advisers
- the peer support service
- our range of information resources

Many members support one another over the phone and provide informal support to each other and share information about their experiences. Sometimes, through friendship, members may arrange phone calls privately and informally with one another. There is currently no guidance in place to support groups who would like to set up formal telephone befriending so this is not a service we currently offer. However, if we decide to do this in the future, we will put appropriate arrangements in place that will apply across the UK.

Befriending

Before 2012 some local groups offered home visiting services. In 2012 these services were stopped as Parkinson’s UK does not have the appropriate training, record-keeping and safeguarding processes in place to deliver home visiting or personal care services through local group volunteers.

The way the charity currently offers a home visit is through Parkinson’s Local Advisers, who provide one-to-one support. Parkinson’s Local Advisers are trained and monitored to ensure they work to agreed standards, and that appropriate safeguarding and support requirements are met.

The volunteering team is working with a small number of local groups in 2014-15 to pilot models for providing a befriending service and there is potential to provide more befriending services in the future.

Some groups have formed partnerships with organisations that do provide home visits and set up a local contract to provide visits for people with Parkinson’s locally. In some areas other charities provide befriending and visiting services that are appropriate for people with Parkinson’s that local groups can signpost to.

Respite

Parkinson's UK does not directly provide respite or sitting services. However, many of our local groups have established successful partnerships with other providers, such as Crossroads, to offer this service underpinned by a formal local contract.

Activities local groups can provide

Singing and dancing and other creative arts

Going to a dance or singing class, taking up painting, or writing a poem are all great ways for people with Parkinson's to take time for themselves. Research studies have suggested that activities like singing and dancing may also improve the quality of life for people with the condition. Lots of people with Parkinson's tell us that they get many benefits from these activities, including the opportunity to meet like-minded people and to do something positive and enjoyable. Activities like dancing also help to keep people moving.
If you would like information to help you organise these activities please contact **creativearts@parkinsons.org.uk** or call **020 7963 3923**.

Other activities could include:

- fundraising events
- carers' meetings
- exercise and therapy sessions
- holidays
- lunches or dinners
- outings
- research activities
- local campaigning

Activities: Things to consider

1. Why has the group decided to provide the activity?
2. How much will the activity cost?
3. What are the risks in providing this activity?
4. Have health and safety issues been considered? Please have a look at the Health and Safety information in section **3B**.
5. Who will be able to access the activity?
6. Are there limitations to the activity?

For example:

- is there a maximum number of sessions a person can access, or
- is there a maximum amount of money per person available?

7. How will the cost be covered?

   Activities are free for people with Parkinson's and carers, some groups ask others to make a contribution up to the full cost to join the activities.

8. If there are limitations, how will you decide who can access the service or activity?

   For example:

   - is it a case of 'first come first served'?
   - is it through referrals from a Parkinson's Nurse or Parkinson's Local Adviser, Occupational Therapist, Physiotherapist etc?
   - on a rota basis?
   - names out of a hat?

9. Who will decide and record who has access to the activity?
   It is best practice to have a small group of people, separate from the committee, responsible for making the decisions. You must decide your criteria and publish them upfront.

10. How will you promote the activity locally to ensure it is available to everybody affected by Parkinson's, whether or not they are members of a local group or of Parkinson's UK?

11. Will you have the correct agreements in place? If you are providing an ongoing activity involving another party, even if there is no cost involved, then a formal agreement needs to be put in place. Sometimes this may simply be signing a venue booking contract for a fixed period. However, it could be necessary to complete a local contract. A standard local contract is available and your local staff team will be able to advise and support you with this. You can also contact the Local Networks team at UK Office who will be able to help email **groupnetwork@parkinsons.org.uk** or call **020 7963 3929**. More information about local contracts is available in section **3E**.

On the next page there is a quick guide about what you need when planning these activities.

Activity	Local contract required?	Risk assessment	Further info
Fundraising events		✓	See section 3B and 5D for more information
Carers' meetings	✓	✓	See section 3B, 3E for more information
Exercise and therapy sessions	✓	✓	See section 3B, 3C and 3E for more information
Holidays		✓	A booking form with supplier is sufficient, also see section 3B and 3C
Lunches or dinners		✓	A booking form with supplier is sufficient also see section 3B and 3C
Outings		✓	A booking form with supplier is sufficient, also see section 3B and 3C
Respite	✓	✓	See section 3B, 3E for more information
Research activities		✓	See section 3B and 5F for more information
Local campaigning		✓	See section 3B and 5E for more information
Singing and dancing	✓	✓	See section 3A, 3B and 3E for more information

3B. HEALTH AND SAFETY

Under the Health and Safety at Work Act 1974 Parkinson's UK must have a written health and safety policy. Copies are available from the Facilities team at UK Office and you can contact them by emailing **facilities@parkinsons.org.uk** or call them on **020 7931 8080**.

Assessing risk

Parkinson's UK actively promotes the reduction of risk to help keep people safe. Local groups are no exception and we've produced five separate risk assessment forms designed for local activities. These are:

- group outings
- group holidays
- street collections
- local group venues
- events and one-off activities

It is best practice for local groups and volunteers to use these forms to help keep their activities safe. These forms are available from the Facilities team at UK Office. You can also access the forms at **parkinsons.org.uk/localgroupresources**. If you are unable to access the webpage, please contact the Local Networks team for a copy, **groupnetwork@parkinonsons.org.uk** or call **0207 963 3929**.

Parkinson's UK has comprehensive insurance cover for local groups and you can find more details in the section **4B** on insurance. It is vital you risk assess all your local group's activities as Parkinson's UK could be held liable for negligence should something go wrong.

Reporting incidents

All incidents/near misses or dangerous occurrences, whether resulting in injury or not, must be reported to the Volunteer Coordinator who will help you complete an Incident Report Form, which will be sent to the Facilities team. For further clarification on this procedure or for a copy of the Accidents and Incidents Investigation Policy and Procedure document, contact the Facilities Team. An Incident Report Form is also available here: **parkinsons.org.uk/localgroupresources**. If you are unable to access the web page please contact the Local Networks team for a copy.

Use of computers

Guidance to assist volunteers using PCs to help them avoid any aches and pains is available from the Facilities team.

Manual handling and lifting

Advice on helping volunteers avoid injury from lifting and carrying is available from the Facilities team.

Food Hygiene

Rules of food hygiene are contained in the Food Safety (General Food Hygiene) Regulations, 1995. The regulations apply to events where food or drink is stored or supplied either on a temporary basis, for example stalls at a fete, or regularly, for example a café in a community centre. These rules apply whether food and drink is sold at a profit or not.

Many of the regulations are common sense. For example you must ensure:

- you use clean premises and equipment
- you have separate places for washing hands and cleaning food
- you keep raw and cooked food separate
- food is carried in clean containers
- non-edible or hazardous substances are clearly labelled
- you don't work with food if you have a skin infection or an upset stomach.

If you are planning to sell food for fundraising events you must display signs informing people that items may contain nuts or other ingredients that could cause a serious allergic reaction. If you are not sure whether the ingredients contain nuts for example, it is best practice to include a sign stating that items "may contain traces of dairy and nuts".

For further information contact your local environmental health department who can advise on food hygiene requirements. You can also contact the Facilities team for advice on health and safety at **facilities@parkinsons.org.uk** or call **020 7931 8080**.

3C. INSURANCE

Local groups are included in our insurance arrangements which cover the activities described below. If you have any questions concerning these arrangements please contact the Facilities team based at UK Office by emailing **facilities@parkinsons.org.uk** or call **020 7931 8080**.

We post a copy of our insurance arrangements to all local groups in July each year following renewal.

Who does our insurance cover?

Our insurance policy covers all attendees at activities organised on behalf of Parkinson's UK, not only members as in the past.

Where we refer to attendees, we mean anyone who is legitimately attending the activity organised by Parkinson's UK volunteers or staff.

Public liability

The insurance covers injury to third parties – including trustees, employees, attendees and volunteers – and damage to property. It also covers 'attendee to attendee', ie if one attendee causes injury to another attendee during an event.

Money raised by volunteers

The insurance covers theft or loss of Parkinson's UK money and local group funds in the hands of volunteers limited to a maximum of £500 in a locked premises or £1,000 in a locked safe or in transit .

Local group property

The insurance covers £15,000 per group, £5,000 on any one item. Loaned items should normally be covered by the borrower's household insurance. It's subject to £500 excess on each claim.

Private motor vehicles

Volunteers driving on behalf of Parkinson's UK should be covered by their own car insurance. It is up to individuals to ensure they have adequate cover.

Personal accident

The insurance covers trustees, employees, volunteers and attendees at local group activities.

Holiday insurance

Trustees, employees, volunteers and attendees are covered for holidays organised by the local group. We don't record medical information, there is no age limit for medical expenses and all attendees are covered.

We define a Parkinson's UK holiday as a holiday organised by Parkinson's UK volunteers for people affected by Parkinson's and paid for through the local group bank account regardless of whether people are asked to contribute to the cost.

Meetings held at private homes

Our insurance policy will cover members whilst on Parkinson's UK business. However there are occasions when people meet at private addresses – for example, committee meetings are occasionally held at a committee member's home. In such circumstances it is useful to consider a couple of examples of possible incidents:

1. If a committee member trips up on a rug that is not securely in place, falls and damages their knee.
2. If a dining chair at a table collapses and a committee member hurts their back.

In cases like these it is unlikely that a court would attach any legal liability to Parkinson's UK as an organisation. It is much more likely that any allegation brought by the injured party will be legally viewed as resting with the property owner. This type of situation is generally covered by household insurance under a Personal Liability section. Property owners are encouraged to check the position with their household insurance company. Our insurance policy will only respond if a legal liability such as negligence rests with Parkinson's UK. As such, it is safest to assume that our insurance does not cover meetings at private addresses.

Events held at private homes

Events that are used to raise funds or gather members of the public together are more likely to be insured by Parkinson's Public Liability insurance. This is because a risk assessment template is provided centrally and is completed for such events. This creates a greater link between the event and Parkinson's UK and therefore increases the likelihood of a court considering that the charity has a legal liability.

However, please do think about situations described above as a court may view Parkinson's UK liable but may also consider the situation to have arisen because the householder has failed to provide a safe venue for the event.

That's why it's very important to carry out a thorough risk assessment. If the risk assessment identifies that the venue is not entirely safe, the event should not be held at that particular venue.

Professionals delivering services

Professionals delivering services are not covered by Parkinson's UK insurance. They must have their own professional insurance as outlined in the Parkinson's UK local contract regardless of whether they are charging a fee or delivering the service free of charge. The local group may pay for this insurance under exceptional circumstances and after discussion with the local team.

3D. SAFEGUARDING

We take people's safety very seriously at Parkinson's UK. That means everyone who works or volunteers for, or represents the charity, needs to show care for and act with integrity towards the people we connect with.

Safeguarding is about keeping vulnerable people safe, especially adults at risk of abuse, while protecting and supporting those who work and volunteer for us. It is important that you are aware of what to look out for and what to do if you're concerned about someone you meet through your volunteering.

Please read our Safeguarding booklet for England, and Northern Ireland, Scotland and Wales, and Guidance for volunteers for more information about what to do if you become aware of a safeguarding issue. The booklets are available from City Digital Limited direct by calling **0845 121 2354** or emailing **resources@parkinsons.org.uk**.

Talk to your staff contact about who to call in your area if you have a safeguarding concern. If you are unable to reach them, or you are not a volunteer or group member and have any safeguarding concerns, please contact the designated protection officer on **safeguarding@parkinsons.org.uk** or call **0344 225 9853**.

For the most up-to-date information on safeguarding visit **parkinsons.org.uk/safeguarding**.

3E. LOCAL CONTRACTS

Local contracts, previously known as service level agreements (or SLAs), are contracts between local groups and organisations/people providing a service or an activity. These contracts ensure that the service/activity being provided meets the needs of local people affected by Parkinson's.

Why do we need them?

The contracts are important for setting expectations for both the group and the service/activity provider. They set out:

- how the service/activity will be provided
- who will be involved
- the practicalities of the service
- how it will be evaluated

Ultimately, the contract outlines a fair and clear agreement which ensures that people affected by Parkinson's receive a high quality service/activity.

How do I start a new contract?

Please contact your local team or the Local Networks team to get a template contract and an outline of the process. There are also supporting documents available to guide groups through all the stages of a new contract, including a checklist of things to consider before setting up a new service/activity and good practice examples.

How do I renew a contract?

The maximum length of a contract is one year and we ask groups to evaluate the service provided before renewing the contract. It's useful to regularly check the service/activity provided as this will help make sure it adapts to meet people's changing needs and any other changes such as the number of participants and their ages.

Do we always need a local contact in place?

For ‘one-off’ activities or services, it is sufficient to have the terms of the agreement in writing, including on email. For any activity or service that takes place on more than one occasion, a local contract must be in place.

For more information please contact the Local Networks team on **groupnetwork@parkinsons.org.uk** or call **020 7963 3929**.

3F. DATA PROTECTION

Under the Data Protection Act 1998, Parkinson's UK has legal obligations whenever it handles personal data.

Personal data is:

- information that identifies a living person which is held on a computer (such as in electronic files, emails, or databases)
- information that identifies a living person which is held in an organised filing system (including, paper files in a filing cabinet or an archive box)

Personal data could include someone's name, address, email address, telephone number and date of birth. Under the Act, we need to make sure the information we keep about people is good quality, relevant, up to date, protected and secure.

Particular care must also be taken when handling sensitive personal data as more restrictive requirements apply to this type of information. This includes details of someone's racial or ethnic origin, political opinions or religious belief and sexual orientation.

If your volunteer role involves handling personal information, you must sign a confidentiality pledge. You'll find a copy here: **parkinsons.org.uk/local groupresources**. If you are unable to access the webpage, please contact the Local Networks team for a copy, **groupnetwork@parkinonsons.org.uk** or call **020 7963 3929**.

Local groups are an integral part of the charity, so the information you handle is ultimately the responsibility of Parkinson's UK. The following checklist will help you think through the issues associated with Data Protection and ensure your local group complies with the Act.

Data Protection check list

You need to consider all of the following:

1. Fair processing.

Is the individual you are collecting information about likely to be aware of the uses you will make of it?

Remember, your group should have a clear understanding of why it needs the information and how it will use it and be prepared to explain this. Think about what these purposes might be.

Put yourself in the shoes of the person whose data is being processed. Ask yourself: "Would I expect my personal details to be used in this way?" If you are unsure whether the individual would be aware of the uses you intend to make of their information, you should tell them – don't wait to be asked.

Think about how your group will do this. This is most easily achieved at the point where an individual's information is collected. For example you could tell them in person or via a privacy notice on the relevant form. Model privacy statements can be found in the charity's Data Protection policy.

2. Sharing

Is the individual you are collecting information about likely to be aware of who you intend to disclose or share it with, outside of Parkinson's UK, and have they been given the opportunity to say they don't want this to happen (to opt out)?

Remember, your group should have a clear understanding of who it may want to disclose or share information with (if at all) and be prepared to explain this. Think about the different professional or other agencies this might include and why. For example this may be sharing the names and medical information of attendees of a planned exercise class with the teacher.

Ask yourself: "Would I expect my personal details to be disclosed or shared in this way?" If you are unsure whether the individual would be aware of how you will disclose or share their information you should tell them – don't wait for them to ask.

Think about how your group will do this. This is most easily achieved at the point where an individual's information is collected eg by telling them in person or via a privacy notice on the relevant form. Model privacy statements can be found in the charity's Data Protection policy.

Remember, local groups are an integral part of Parkinson's UK, so communicating information about your members, volunteers and supporters within the charity (eg to staff) does not constitute disclosure or sharing.

3. Marketing

Has the individual been given the opportunity to say they don't want to receive any of the marketing materials you may wish to circulate to them?

Remember, people have a legal right not to receive marking materials from the charity, including those sent by local groups. In general this relates to any communication with "an ask" attached, such as fundraising or calls for support. Think about whether any of the communications your group may wish to send fall within this category.

Think about how your group will give individuals the opportunity to opt out. This is most easily achieved at the point where an individual's information is collected eg by asking them in person or via a privacy notice on the relevant form. Model privacy statements can be found in the charity's Data Protection policy.

You need to take particular care if you want to carry out any marketing activities by phone or email. These are considered to be more intrusive than using post and there is a legal requirement to have asked an individual's permission before carrying out any marketing in this way.

4. Relevance

Is all the information being collected about the individual justifiable?

Remember, your group should only collect information it actually needs, ensuring it is adequate, relevant and not excessive. If information is not strictly needed, it should not be collected. Information that is no longer required should be deleted.

5. Accuracy

Are there procedures in place to ensure the accuracy of the information?

Remember, your group must take reasonable steps to ensure the information it handles is up-to-date.

Think about how your group might achieve this. This does not have to be complicated but it should be clear who is responsible for keeping the group's records up-to-date. You also need to check with your members, volunteers and supporters that the information held on them is accurate. For example, you could encourage individuals to inform you of any updates or changes in their details via your newsletter.

6. Retention and disposal

Is there a clear period of time for retaining the information your group collects and are there procedures for secure storage or the removal/destruction of this information, if necessary?

Remember, your group must only handle information for as long as it needs it.

Think about what information your group needs to keep, the time you need to keep it for and who will be responsible for the archiving or removal/destruction of information as required.

In particular thought should be given to how your group manages the following information which is a minimum requirement:

- Committee minutes from the whole length of time the group has been running.
- Financial records from the last six years and the current year.
- Membership records.

7. Confidentiality

Is access to information limited to those who need it and are they aware of the extent to which the information is confidential?

Remember, information should only be accessed on a need-to-know basis.

Think about who legitimately needs access to the information your group handles. This is likely to include those responsible for running the group and other charity staff. It should be made clear to these individuals what information is confidential and who is allowed access to the information.

8. Security

Are there adequate security measures in place to protect the information, especially when it is moved about (in transit)?

Remember, your group must take reasonable steps to ensure that the information it handles is secure. This includes protecting it against unauthorized access, accidental loss or destruction or damage.

Think about how your group might achieve this. For example ensuring that electronic files are password protected and paper copies are stored in a locked cabinet.

9. Processing

Will a third party be engaged to handle any of the information on the group's behalf (a data processor)?

Remember, though the use of data processors is permitted under the Act, the information remains the charity's responsibility.

Think about the steps your group can take to ensure the information will be adequately protected. For example, if you are going to use a third party, you will need a contract with them that specifically sets out their Data Protection responsibilities. For advice on contracts please contact the Local Networks team at the UK Office at **groupnetwork@parkinsons.org.uk** or call **020 7963 3929** or email.

10. Transfer abroad

Will any of the information be transferred abroad?

Remember, information should not be transferred outside the European Economic Area unless you can ensure it will be adequately protected. For advice on transferring information abroad contact the Local Networks Team at the UK Office.

11. Subject access

Is the individual aware of their right to make a subject access request?

Remember, individuals have a legal right to request a copy of the information the Charity handles about them including that held by local groups. This may include (but is not limited to):

- internal documents (whether electronic and in hard copy)
- emails relating to charity business (even if these are sent from personal email account).
- comments made in the public domain relating to charity business (eg on social media, online forums etc)

There are specific criteria and time limits for dealing with a subject access request and so all requests should be referred to the Data Protection Officer at the UK Office immediately. Any individual who wants to make a subject access request should be advised to do so in writing and address this to the Data Protection Officer.

It is important to report any data protection-related incidents to your staff contact as soon as possible so that any adverse effects can be minimised. Please speak to them if you have any questions or concerns about this issue.

Please also read our policy on data protection (to be launched summer 2015).

Alternatively contact the Data Protection Officer at the UK Office at **governance@parkinsons.org.uk** or call **020 7932 1327**.

12. Confidentiality

The charity owes a legal duty of confidentiality to the people we hold information about. That means restricting access to information to those who "need to know".

Remember, Parkinson's UK does not sell personal data, and in general does not share it with third parties unless it is legally obligated to or has someone's consent.

Confidentiality is also an essential principle of the services we provide. So, to ensure that the people and organisations we work with trust us, it is vital that you understand what information we can and cannot share.

Think about the care you need to take if someone shares personal information with you in the course of your role. For example, a carer could discuss their finances. You must be careful not to share this information with others who don't have a strict need-to-know as it can easily become gossip. Confidentiality is still important even if a situation might seem informal.

Your staff contact can help with anything that you're concerned about around this issue and other formal support is available to volunteers in certain roles.

If your volunteer role involves handling confidential information, you must sign a **confidentiality pledge**. A copy is available here: **parkinsons.org.uk/localgroupresources**. Report confidentiality-related incidents to your staff contact as soon as possible so that any adverse effects can be minimised. Please speak to them if you have any questions or concerns about this issue.

Alternatively contact the Data Protection Officer at the UK Office at **governance@parkinsons.org.uk** or call **020 7932 1327**. If you are unable to access the webpage, please contact the Local Networks team for a copy, **groupnetwork@parkinonsons.org.uk** or call **0207 963 3929**.


PARKINSON'S UK
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4.

LOCAL GROUP FINANCES

4A. MANAGING THE CHARITY'S FINANCES

The local group network is part of the legal entity 'Parkinson's UK'. As one charity we share the same goals. Any funds raised, whether locally or centrally, are done so on behalf of Parkinson's UK.

What you need to know

It is important to remember that it is not solely the responsibility of the treasurer to make financial decisions on behalf of a group. There are procedures that must be followed:

- In branches, financial decisions must be made by the committee (including the treasurer) and formally minuted.
- In support groups, financial recommendations must be made to the group and decisions should be made by consensus and minutes of the meeting must be kept.

Use of funds

Local groups take on a custodial role and are responsible for the safe-keeping of the charity's local funds. These funds must only be used to support the aims and objectives of the charity and for activities within the guidance provided for local groups.

Training and guidance are available for all volunteers responsible for a group's financial activity. The Treasurer's guide provides information on all aspects of managing group finances from opening a current account to planning and budgeting.

If your group does not have a copy of the Treasurer's guide or to find out more about Treasurer's training please contact your Volunteer Coordinator or the Local Networks Finance team at **treasurers@parkinsons.org.uk** or call **020 7932 1324**.

You can find a copy of the Treasurer's guide as well as other useful resources on our website: **parkinsons.org.uk/treasurers**

4B. THE FINANCIAL FRAMEWORK

In May 2013 the Board of Trustees approved the local group financial framework which outlines the policy for the level of reserves held by groups. The financial framework aims to:

- improve predictability and stability of funding, helping us to meet the needs of people affected by Parkinson's
- invest excess reserves held by the local groups so the Charity can meet its vision
- increase donor confidence leading to higher levels of donations
- support local groups to plan and manage their resources effectively

This framework supports your group's activities and will increase financial confidence throughout the charity.

Your group can hold up to one year's worth of local expenditure as your reserves. This means that if your group were not to receive a penny of income, your group should still be able to fund a full year's worth of your planned activities. After this your group is required to use any remaining funds to support centrally funded activities.

To support this, your group must complete the budget template and agree this with your local team. The budget template will help determine the amount available to transfer to support centrally funded activities. This process is repeated each year.

Planning and budgeting

Your group must discuss and agree a budget for the financial year and agree this with your area or country team.

Your budget should be prepared in consultation with the group (in a branch this is the responsibility of the committee). Your treasurer will generally be responsible for putting the agreed figures into the budget template.

A budget will help you to:

- manage your funds
- identify and control costs
- identify what income you need to cover your costs

- identify your priorities and focus on what the main activities of the local group will be over the coming year
- identify potential problems with your finances, eg a shortfall in income
- calculate your level of local group reserves (which must be equivalent to a maximum of 12 months' worth of expenditure) and the amount of surplus funds to transfer
- think about new initiatives and the future of your group

More information on planning and budgeting is available in the Treasurer's Guide.
For a copy of the Financial Framework policy, please contact the Local Networks Finance team at **treasurers@parkinsons.org.uk** or call **020 7932 1324**.

4C. LEGACIES

Legacies are an enormously important source of income for Parkinson's UK. A legacy may be left to Parkinson's UK or to a Parkinson's UK local group by a member, volunteer or the public.

Each legacy left to Parkinson's UK is treated with the same diligence, whether they are a general gift to Parkinson's UK or a gift to a specific part of the Local Network. Due to the nature of legacy administration, all legacies are dealt with at Parkinson's UK Office.

In 2012 we introduced a revised policy. This helps us to make sure that all legacies left to Parkinson's UK local groups are used to support the charity's objectives of finding a cure and improving life for everyone affected by Parkinson's. The key points are:

- when a local group is to receive a legacy under £5,000, they will be informed by the UK Office and the money will be transferred to the local group once Parkinson's UK receive it
- when a local group is to receive a legacy of £5,000 or more the group will need to submit a legacy spending plan before the money can be transferred

More information and a copy of the Local Groups Legacy Policy is available from your Volunteer Coordinator or the Local Group Network team at the UK Office who you can email at **groupnetwork@parkinsons.org.uk** or call **020 7963 3929**.

4D. FINANCIAL ASSISTANCE

The services and support we offer to people affected by Parkinson's were recently reviewed by the Board of Trustees. As part of this the Board decided that Parkinson's UK will continue to offer grants to individuals in need.

However, we are aware that the way we offer funding via local groups and the Mali Jenkins fund does not reach everybody who needs our help. We are unable to promote the Mali Jenkins fund as widely as we would like as this may result in levels of demand that we can't meet as our funds are limited.

We need to find a better way of providing financial assistance and will be looking at ways of doing so. In the meantime, Parkinson's UK has decided to suspend the Mali Jenkins fund from July 2015. We will use this as an opportunity to explore alternative options and put in place new arrangements that enable us to provide more effective financial assistance to those who need our help.

You can find information about other sources of grant funding for people affected by Parkinson's by visiting the website of Turn2us: **www.turn2us.org.uk/grants**

Purchasing or loaning equipment

Local groups are sometimes asked to purchase equipment for people affected by Parkinson's to help with daily living tasks. These include items such as electrical equipment, specialised chairs, pill timers, metronomes and exercise bikes.

It's vital that you consider any potential health and safety issues before buying an item of equipment for an individual. If you are buying an item of daily living equipment for someone, their needs must be fully assessed by a qualified person prior to purchase (eg an occupational therapist, speech and language therapist, physiotherapist). An email from the therapist is enough to confirm that an assessment has taken place, providing it gives specific details of the equipment required. A therapist may also be able to obtain the item at a lower price than a local group and help ensure there are proper maintenance and repair procedures in place.

Once someone has received an item of equipment, the ongoing costs and maintenance are their responsibility and not that of the local group.

If an item of equipment is purchased for someone, they must sign a disclaimer form to ensure that Parkinson's UK is not held responsible should there be injury as a result of using the equipment. A template disclaimer form is available here **parkinsons.org.uk/local groupresources**. If you are unable to access the webpage, please contact the Local Networks team for a copy, **groupnetwork@parkinonsons.org.uk** or call **0207 963 3929**.

With the exception of Wii Fit, local groups should not buy items and lend them to individuals to be returned when they are no longer required. It may not be appropriate to lend the equipment to someone else as the item my not meet the next person's needs. A Wii Fit disclaimer form is available here **parkinsons.org.uk/local groupresources**. If you are unable to access the webpage, please contact the Local Networks team for a copy, **groupnetwork@parkinonsons.org.uk** or call **0207 963 3929**.

PRICE LIST

PEN	£1
PIN BADGE	£1
TROLLEY COIN	£1.50
HIGHCLERE T-SHIRTS	£6.50
BIG NOODLE	£19.95
NOODLE	£8.50
MUG	£3

5.

TALKING ABOUT PARKINSON'S UK

5A. BRAND AND MARKETING

What is marketing?

Marketing is the many different ways Parkinson's UK communicates with the outside world. We're all involved in marketing every day, even if we don't realise it. Every time you tell someone what Parkinson's is like, or talk about the charity, you're helping to raise awareness – and that's marketing.

Marketing is more than just advertising, selling and promotions – it's the whole process of finding out who your audiences are, what is the right message for them and communicating with them at the right time in the best possible way. All of this helps us raise money to fund our vital work. It also raises awareness of the condition, helping to change public attitudes and improve life for people affected by Parkinson's.

What is the Parkinson's UK brand?

Our brand is the way we look and how we speak. It's also who we are, which we define through our core values:

- We listen
- We unite
- We inspire
- We innovate
- We're inclusive
- We focus

Our brand and core values help everyone involved with the charity to act and communicate in a consistent way, which ensures the general public know and trust Parkinson's UK. It's really important that every communication we send out is 'on brand' because this ensures the whole organisation is speaking with the same voice and we are putting out a consistently strong message to the public.

To find more information about our brand, please visit parkinsons.org.uk/brand. We have resources available that cover 'talking about us'. Please contact the Marketing team for further information at **marketing@parkinsons.org.uk** or call **0800 652 9878**.

How can I raise awareness of Parkinson's UK?

The best place to start is our Marketing Recipe Book. This provides all the ingredients you need to cook up successful awareness raising activity in your local area. It lists different types of communications, such as 'awareness raising', and all our current information resources and branded materials that are most relevant for this kind of activity. To keep you informed of the latest messages and supporting materials, the Marketing Recipe Book is updated with new recipe cards every year.

One recipe book per local group is available via your local Volunteer Coordinator. For more information about the Marketing Recipe Book please email **marketing@parkinsons.org.uk**.

If you'd like to design your own Parkinson's UK branded materials, you can use the online template system. This allows you to easily create marketing materials to publicise your local activities. We have simple poster and flyer templates on the internet which you can personalise with your details such as date, time and location as well as an image. The designs are then printed through our print and distribution house, City Digital Limited (CDL), giving a professional quality finish. You can access the website and a guide here: **parkinsons.org.uk/templates**.

As well as the online template system we have some text only poster and flyer templates available, which use Microsoft Office software. If you would like to use these templates please contact the Marketing team at **marketing@parkinsons.org.uk** or call **0800 652 8978**.

Lastly, we understand that some of you are already doing a lot of awareness raising in your local area and may be able to support other local groups who have a specific communication challenge and are unsure about how to solve it. If so, we would be happy to help you become brand ambassadors.

If you would like to register your interest for more information about this, please contact the **Marketing team marketing@parkinsons.org.uk** or call **0800 652 8978**.

What does the Marketing team do?

The Marketing team at Parkinson's UK aims to equip teams and volunteers across the charity with the tools needed to shout about their work and get their message to the right people.

We want to help you spread the word about Parkinson's UK and ensure you have the right information and materials for what you want to do. If you have any questions about marketing please email **marketing@parkinsons.org.uk** or call **0800 652 8978**.

We work closely with the Editorial and Creative team who create all of our resources. If you have any questions about ordering resources please contact them at **resources@parkinsons.org.uk** or call **0845 121 2354**.

Parkinson’s Awareness Week

Parkinson’s Awareness Week offers a unique opportunity for us to raise awareness and change attitudes about the condition with the general public.

Each year a focus is chosen for Parkinson’s Awareness Week. People affected by Parkinson’s are always consulted about this to make sure we communicate the right issues to the public in the best possible way.

Local groups are a very important part of Parkinson’s Awareness Week and do great work organising awareness and fundraising events. We aim to provide you with all the information and resources you need. You’ll find more information about Parkinson’s Awareness Week and the support available to you here **parkinsons.org.uk/awarenessweek**.

Can I get involved in the development of Parkinson’s UK marketing materials?

Yes please! We are always looking for more people to join our marketing user panel.
This panel is made up of people affected by Parkinson’s who are happy to be emailed to feedback on the ideas and development of campaigns and materials. To find out more email **marketing@parkinsons.org.uk**.

5B. MEDIA AND PR

Local media can help local groups to raise awareness of Parkinson's, Parkinson's UK and the support the charity and the local group can offer to anyone affected by Parkinson's in the area. It is also a great way of promoting local activities and events.

The main types of media

- newspapers
- magazine
- radio
- television
- online

Getting media coverage

Typically, the kind of group activities that the media will cover are:

- details of branch/support group meetings
- fundraising activity
- campaigning activity
- open days/awareness raising
- Parkinson's Awareness Week

However, due to an ever-changing news agenda, it is almost impossible to guarantee media coverage. For this reason the UK office has a dedicated team of Media and PR officers who can help with any media requests that come to local groups.

In order to maximise the chances of getting coverage in your local area, all media requests should go through the Media and PR team.

How can the Media and PR team help?

There are a number of ways the Media and PR team can help you with contacting your local media, including:

- press releases
- letters to the editor
- features
- briefing spokespeople for interviews
- photo opportunities
- facts and figures for journalists about Parkinson's, how many people are affected, treatments and the work of Parkinson's UK

Get in touch

If you need support or have any activities that you would like to discuss media opportunities around, please email the team on **pr@parkinsons.org.uk** or call **020 7963 9370**.

5C. PROMOTING YOUR GROUP ONLINE

For many people affected by Parkinson's, searching for information and support online will be their first connection with Parkinson's UK. This includes finding out about local groups.

Your group's pages on the Parkinson's UK website

Each local group has an area on the Parkinson's UK website, which is often the first contact with the charity for people affected by Parkinson's. This includes details of your meetings and activities, and contact information. An events and/or news page can also be added. It's vital for putting people in touch with local support so it's really important to make sure that details for your group are up to date.

To do this you must fill out the local group update template that can be found at: **parkinsons.org.uk/localgroupweb**. When you have filled in the relevant changes, email the template to **web@parkinsons.org.uk**.

It's vital that these pages are concise and easy to understand without jargon or acronyms. Make sure that if you direct people to contact a particular person you include their contact details, with their permission.

Each branch and support group has a 'friendly' web address that you can share with people to promote your group (eg **parkinsons.org.uk/portsmouth**). If you do not know your address, ask the Digital team whose details are at the end of this section.

Local group external websites and social media

Some groups set up their own websites or social media pages as a way of providing more information and support for their members and new people.

If you're thinking about doing this, you must consider whether you really need something separate. If the purpose is to let people know about your activities and how to get in touch, this is already available through the Parkinson's UK website and we will support you to keep this up-to-date. If you go ahead with something separate, you must:

- be committed to providing the ongoing maintenance and support required to run a website or page
- ensure content is up to date, accurate and in line with the charity's messaging
- use our logo and legal information

For more information and specific guidance, see **parkinsons.org.uk/localgroupweb**.

Other Parkinson's support online

People in your group may benefit from Parkinson's information and support online. Here are other ways they can access this.

Parkinson's UK website

parkinsons.org.uk
Visit the Parkinson's UK website regularly to find out Parkinson's information and support, the latest news, and stories from people living with Parkinson's.

Forum

parkinsons.org.uk/forum
A space on our website for people affected by Parkinson's to share information and experiences, ask questions and support one another, any time, day or night.

Social Media

Like Parkinson's UK on Facebook **facebook.com/parkinsonsuk**.
Follow Parkinson's UK on Twitter **twitter.com/parkinsonsuk**.

Any questions?

If you're unsure of anything in this section or have any questions then please get in touch with our friendly Digital team who will be able to advise you further. You can email us at **web@parkinsons.org.uk** or call **020 7963 3919**.

5D. FUNDRAISING

As a local group you will need funds for your running costs and to cover the cost of any local services you provide. You may also want to raise funds to support the work of Parkinson's UK in general. This could be Parkinson's nurses, information and support or research amongst other things.

What to do

Before you plan how to raise funds, you need to be clear why you are fundraising. You then need to check on legalities, set targets and decide how to fundraise.

The Regional Fundraising team can will help you understand the law around fundraising and give you an idea of which fundraising method will work for you and your local group, and how to go about it. Please contact the Regional Fundraising team at **fundraising@parkinsons.org.uk** or call **020 7963 3912**.

Your regional fundraiser

Every region or country in the UK has its own regional fundraiser and they are there to support you with your fundraising as well as raising funds and awareness for the wider charity across the local community. They can offer useful fundraising hints and ideas and also ensure you are well aware of all of the relevant rules and regulations.

Whether you need tips for organising an event, guidance about contacting local press, letters of authorisation to contact local businesses or even someone to come along and give a talk – your regional fundraiser can help.

They can answer your fundraising questions, offer advice and even provide fundraising materials – so do get in touch!

5E. CAMPAIGNING

Local groups have a unique opportunity to campaign to make their area better for people affected by Parkinson's. This could be for better health and social care services or better treatment in shops. You will know the services in your area and the needs of your community best.

Campaigning doesn't have to be a big undertaking. What is important is making sure the voices of people with Parkinson's are being heard in your area. Depending on the situation, this can range from building good relationships with your local decision makers to putting together a petition about services. Whatever you want to campaign for, we're here to support you.

Building a relationship with decision makers

Even if you don't have a particular issue you want to improve, it's still sensible to build a relationship with local decision makers. Depending on where you live, this could be your Member of Parliament, Welsh Assembly Member, Member of Scottish Parliament or Member of Legislative Assembly in Northern Ireland.

You can also build relationships with people on the council, health boards/clinical commissioning groups and patient participation groups.

Achieving this can be as simple as inviting them to one of your meetings. This gives the opportunity for them to learn more about Parkinson's, understand how it affects your members and see the work your group does. You can, of course, also learn more about the work they do and how it affects you.

A good relationship means that they are likely to take your needs into consideration when making decisions and be more receptive to any issues you bring them in the future. There is more information about the different decision makers and tips on meeting them in our **campaigns toolkit: campaign for people living with Parkinson's** which you can find at **parkinsons.org.uk/campaignstoolkit** or call **020 7963 9349**.

Support and resources

We are happy to support you in any way we can. If you have any questions or are worried or unhappy with a service, get in touch and we'll work with you to develop a plan to try and improve it. Just email **campaigns@parkinsons.org.uk** or call **020 7963 9349**.

Campaigns Network

If you want to be part of our national campaigns you can join the Parkinson's UK Campaigns Network. You'll be sent emails once a month with an action you can take such as signing a petition or emailing an MP. You'll also be kept up-to-date with how the campaigns you get involved with are going, so you can see the improvements we're achieving together.
You can sign up online **parkinsons.org.uk/campaignsnetwork**.

5F. OUR RESEARCH

Parkinson's UK is the largest charitable funder of Parkinson's research in Europe. Since 1969, we've invested almost £70million in groundbreaking research, currently supporting more than 60 research projects worth over £20million. In 2014 we invested over £5 million in research, supporting more than 20 new research projects.

Supporting research

Without the support of our local groups, donors and members, we simply would not be able to fund this vital research. If your groups would like to support research, there a couple of ways you can do this:

- Supporting research generally – just add a short note to your donation so we know.
- You can choose to support a specific project through our 'Adopt a project' scheme – for further information please contact the Research team at **rsn@parkinsons.org.uk**.

How do we fund research?

As we are entirely dependent on voluntary donations, it's vital that we use these donations to support only the highest quality research that really will make a difference for people with Parkinson's. To ensure we do this funds are only awarded after applications from researchers have been through a rigorous review process by both experts in the field and people affected by Parkinson's.

Local groups must not commission research or donate directly to a research team. All the research the Parkinson's UK supports must go through our rigorous review process under the terms of our membership to the Association of Medical Research Charities (AMRC) before funds can be awarded.

You can read more about how we fund research here –
parkinsons.org.uk/fundingresearch

Getting involved in research

Parkinson's UK is committed to ensuring that people affected by Parkinson's have access to research and that, of course, includes our local groups. We aim to keep you up to date with all the latest research news and opportunities to participate in research and work with the research community to shape vital research.

There are lots of different ways local groups and anyone who is interested can find out about Parkinson's research.

Join our Research Support Network

The Parkinson's UK Research Support Network is an online network for people driven to help find a cure and better treatments for Parkinson's. It's free to join and our members receive regular updates about research news, events, and opportunities to participate in research and work with the research community to shape research. You can do this at **parkinsons.org.uk/researchsupportnetwork**.

Keeping up-to-date

You can keep up to date with all the latest developments in Parkinson's research through:

- the research news section of our website: **parkinsons.org.uk/researchnews**
- the latest issue of our research magazine 'Progress': **parkinsons.org.uk/progress**
- following us on Facebook – **facebook.com/parkinsonsuk**
- or on Twitter – **twitter.com/parkinsonsuk**

Come along to a research event

We hold free national and local research events across the UK and would really encourage local groups with an interest in research to come along. Visit a researcher in their lab, spend the day at our Brain Bank or go along to a university open day and find out what goes on at the forefront of research. Find out about upcoming research events at **parkinsons.org.uk/researchevents**.

Work with the research team

Volunteers are a vital part of the work of the research team and we have a number of volunteer roles which are essential for carrying out our work. From championing research in your local groups to reviewing grant applications from researchers there are lots of ways you can get involved. Contact us at **rsn@parkinsons.org.uk** or on **020 7963 9398** to find out more about our research volunteer roles.

5G. WORKING WITH PARKINSON'S UK CELEBRITY SUPPORTERS

Most of the high profile people that support Parkinson's UK do so because they have a personal connection to Parkinson's, for example family or friends affected by the condition. We need to work with them in a similar way to other volunteers and families that we support.

Having someone that people recognise talking about Parkinson's in the media, attending events and backing campaigns is invaluable for raising awareness of our work to the charity so it's important we use their support appropriately and that they have a central point of contact at Parkinson's UK.

How to ask for celebrity support

It's vital that any celebrity who already supports Parkinson's UK is approached by the celebrity team, based in the UK Office. This is to ensure:

- continuity in the relationship
- we don't put in too many requests
- we use the celebrity's support appropriately to add the most value to the work of the charity

If our celebrity supporters were approached by every local group or individual fundraiser they would be inundated with requests. The celebrity team know what requests have already been submitted to the celebrity, as well as the support the celebrity has agreed to give to the charity. In some cases the supporter has only agreed to provide quotes of support, or to tweet, or to attend or support a certain number of events, projects or campaigns throughout the year.

If you are thinking about inviting a celebrity, the celebrity team has a direct relationship with the celebrity supporters, and/or their agents, so they can easily update you on what support each celebrity can offer. Going through the celebrity team means that your request will go to the correct person and is appropriate to the relationship that the celebrity supporter has with Parkinson's UK.

Things to consider

If you think that a celebrity could help support something you're doing, you need to be clear how this celebrity's support could benefit you. Here are some questions you might want to consider (your local staff contact or regional fundraiser could also help you with this):

- Think about why you want a Parkinson's UK celebrity supporter to be involved, for example attending an event, donating a signed item, giving a quote of support, and what value they would bring.
- Is there a suitable locally based celebrity who might be more appropriate, such as a local radio presenter or news reader?
- Would a picture and a quote of support from a celebrity supporter be more appropriate and work just as well as someone attending?
- Do you have the budget to pay for a celebrity supporter's travel, hotel (if appropriate) and subsistence if required?

Once you have answered these questions you should be clear on whether celebrity support is necessary and appropriate. If you would still like to explore celebrity supporter availability, the next step is to speak to your Volunteer Coordinator or regional fundraiser. Please provide them with full details of the event or project, what you would like the celebrity to do, what deadlines you are working to, what value you think celebrity support would bring and any names that you are specifically thinking of.

They will check our central database Raiser's Edge or speak to the central celebrity team to see which celebrities already support Parkinson's UK and whether a request to them would be appropriate.

Can you help Parkinson's UK engage more high profile supporters?

Celebrities who have a connection with Parkinson's are a big help to us. So if you or any of your contacts know of anyone in your area, please let your local staff contact or regional fundraiser know so that they can put you in contact with the celebrity team.

Some high profile people are involved in local groups – they could be honorary Presidents, Chairs or members. Please could you also let your local staff contact know if this is the case so they can see if the celebrity can help us. You can be sure they will tell you if they are going to approach this celebrity. For example Jilly Cooper supported a UK campaign in Carers Week and the celebrity team liaised with the local group that Jilly is a member of to keep them in the loop.

If we work together we can ensure our high profile supporters feel valued and that they add value to Parkinson's UK.You can contact the Celebrity team on **celebrity@parkinsons.org.uk** or call **020 7963 9303** or speak to your Volunteer Coordinator or regional fundraiser.

NOTES


BEST COMEDY
OLIVIER AWARD 2007
2 TONY AWARDS 2008
THE 39 STEPS
HITCHCOCK MEETS HILARIOUS!
CRITERION
BEST NEW COMEDY
Lillywhites
THE WORLD'S FINEST SPORTS STORE
LONSDALE
#INMYSHOES
PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by 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

The Helplines Association
Member