

Singing, Wellbeing and Health:  
context, evidence and practice

# Singing and people with Parkinson's

Trish Vella-Burrows and Grenville Hancox



## Singing, Wellbeing and Health: context, evidence and practice

Series Editor: Stephen Clift

The aim of this series is to offer guidance on setting up and running singing groups for people with a range of enduring health issues.

They are based on previous research, the learning from singing for health projects in the UK, and the practical experience of members of the Sidney De Haan Research Centre in establishing and evaluating community singing projects since 2004.

1. Singing and Mental Health – Ian Morrison and Stephen Clift
2. Singing and people with COPD – Ian Morrison and Stephen Clift
3. Singing and people with Dementia – Trish Vella-Burrows
4. Singing and people with Parkinson's – Trish Vella-Burrows and Grenville Hancox

Further resources to supplement this guide can be found online at:

[www.canterbury.ac.uk/research/centres/SDHR](http://www.canterbury.ac.uk/research/centres/SDHR)

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# Introduction

## Aims of this guide

This guide provides an overview of the evidence that group singing can be beneficial for people living with Parkinson's. It also gives examples of setting up singing groups for people living in the community who are affected by the condition. This includes care-givers, family members and friends.

Whilst hospitals may be used as a community singing venue, this guide is not concerned with specialised music therapy as a clinical intervention. Such work is undertaken by registered music therapists, often as part of a multi-disciplinary health team. Rather the guide draws upon the experience of people who live with the effects of Parkinson's and who sing in various established, Parkinson's-focused singing groups. It also draws on the experiences of music practitioners with considerable experience of running such groups. It draws especially upon the experience of music practitioners and health researchers in the Sidney De Haan Research Centre for Arts and Health who have contributed significantly to the growing body of evidence and who have established networks of singing groups for people with specific health conditions, including those affected by Parkinson's.

## Who is this guide for?

This guide is for anyone interested to setting up, running and evaluating community singing groups for the benefit of people living with Parkinson's. This includes:

- Health professionals who are interested in supporting the development of evidence-based and effective community activities which can help promote and maintain wellbeing
- Managers of voluntary sector organisations working with people with Parkinson's in the community who would like to set up singing groups
- Managers of funding bodies interested in supporting innovative health and community activities
- People who are directly affected by Parkinson's
- Family, relatives and friends of people with Parkinson's who are looking for an effective means of engagement and social support for their loved ones
- Experienced community musicians interested in setting up singing for health groups with people affected by Parkinson's

## What this guide offers

Information is provided on evidence from case studies and research projects, and links to further resources and training. This is not intended as a practical toolkit, but to guide and inform.

# Context

## The nature and scale of Parkinson's in the UK

The national charity, Parkinson's UK, estimates that around 127,000 people currently live with Parkinson's in the UK – that is just over one in 500 people. The condition affects men more than women. It is more frequent in people aged 50 and over but one in twenty people with Parkinson's is under the age of 40 (Parkinson's UK, undated a). Currently, there is no known cure for Parkinson's. The causes are also largely unknown although an element of genetic programming has been identified.

Parkinson's is a progressive condition that affects the brain. It is caused by the death of brain cells that produce the chemical messenger dopamine. Dopamine deficiency causes various problems with physical and motor function, sensory function, cognition and communication. People with the condition are affected in different ways but the most common symptoms are slowness of movement, resting tremor and muscular rigidity. Balance and postural problems can lead to 'freezing' episodes, wherein people cannot initiate movement. These problems, together with poor foot-clearance and step-shuffling, lead to an increased tendency to fall (Bloem et al., 2004).

Other common symptoms include: slurring and stuttering of speech and poor voice projection due to lax muscle tone in the face, mouth and throat; visual disturbances; painful muscle cramps; skin conditions; bladder and bowel problems, and postural hypotension (rapid fall in blood pressure when standing) (Wishart and Macphee, 2010). In addition to these physical symptoms, people with Parkinson's may face fatigue and apathy; memory loss; sleep disturbance; mood disorders such as depression, anxiety and/or euphoria; psychological disorders such as compulsive behaviour; psychiatric conditions such as psychosis, hallucinations and delirium. When these latter symptoms are severe, people are given the label of dementia (Aragon et al., 2007). The progressive nature of the condition inevitably leads to symptom-controlling drug intervention at some level, and a need for increased care services, including for some, admission into long-term residential care.

Text-book descriptions of the symptoms of Parkinson's provide an overview of what people with the condition are likely to experience. However, the impact on an individual's quality of life will be unique and will depend on the specific symptoms they experience and the level of their severity, and how they are perceived (Parkinson's UK (undated a)). These perceptions are influenced by: personal circumstances and relationships; personality and approach to life; the effect of the symptoms on practical, emotional, psychological and spiritual elements of life and the support that is available (PDS, 2009a).

In the earlier stages of Parkinson's, symptoms of forgetfulness, apathy, excessive tiredness, stress, depression and poor physical health are not often recognised as signs of Parkinson's. Delayed presentation to a GP and misdiagnoses before the appearance of the better-known symptoms is common and can mean that discussions between the doctor and the patient on the best approach for treatment and support do not take place early enough. This is important because whilst doctors are reluctant to use drugs treatments too early due to their common and undesirable longer-term side effects, alternative forms of support can be very effective. The positive effects of alternative support apply equally to care-givers who observe the changes in their loved-ones and experience the consequences in their own way.

## The medical model of illness

The medical model of illness views ill-health conditions from a scientific perspective, focusing largely on causes, prevalence, progress of symptoms and cures. Currently there is no definitive understanding of the cause(s) of Parkinson's and no known cure, but there are a number of drugs that help to manage the progressive symptoms. The drug L-dopa, used in various formulations, has been the standard treatment for dopamine deficiency for over 30 years. L-dopa and, in some cases, a surgical procedure, can help by directly stimulating the brain to produce more dopamine, or by blocking enzymes that prevent it working effectively. Replacing dopamine in this way is known to improve both motor and non-motor symptoms (Remy et al., 2005). In addition, drugs such as pain-killers, night sedation and gastro-intestinal regulators can help to control other distressing symptoms (Isaacson and Hauser, 2009).

Whilst these drugs undoubtedly provide some symptom-relief, it is known that their longer-term use can cause unwanted side effects. The side effects of L-dopa, for example, include nausea, vomiting and diarrhoea; dyskinesia (involuntary, jerky movements), and heart, lung and renal complications. Perversely, other side effects, such as depression, delirium and compulsive behaviour, mirror symptoms of Parkinson's itself (Wishart and Macphee, 2011).

Coping with side-effects of drugs on top of the symptoms can result in a downward spiral in physical and mental health. Associated with this is a breakdown in carer/cared-for relationships, which may also lead to social withdrawal and increasing isolation for both, and premature admission into long-term care for the person with Parkinson's. It is for these reasons that, alongside the clinical support there is a growing interest in alternative and complementary therapies.

More commonly used non-drug therapies for people with Parkinson's include: the well-established Lee Silverman Voice Treatment, administered by speech and language therapists, which focuses on increased vocal volume and effort (Fox et al., 2002), acupuncture, aromatherapy, chiropractic, herbal medicine, massage, osteopathy, reflexology, Tai chi, yoga and music therapy (PDS, 2009b). These therapies have the potential to address some of the specific symptoms and problems of Parkinson's and broader quality of life issues, with few, or no, harmful side effects. Tai Chi, yoga and music therapy can have the added dimension of social interaction, which is identified as crucially important in supporting the wellbeing for people living directly with Parkinson's and their carers as the condition progresses (O'Reilly et al., 1996).

## Alternative models of illness and Parkinson's

There is no doubt that the dominance of the medical model over the last two centuries has led to the development of life-prolonging/saving treatments. However, the model's emphasis on the science of illness and cure does not necessarily relate well to people's day-to-day experience of living with Parkinson's (Caap-Ahlgren and Dehlin, 2004). An alternative to the medical model is the salutogenic model. This focuses on how people comprehend, manage and make meaning of their lives even when faced with significant health disruptions (Sidell, 2007) such as Parkinson's.

Developed by Aaron Antonovsky in the 1970s, the salutogenic model of health takes into account the factors that affect an individual's ability to adjust to health changes (Antonovsky, 1979; Sidell, 2007). From the salutogenic point of view, the condition of Parkinson's is associated with profound and prolonged adjustment, for the people living with the condition and those closest to them.

These adjustments relate to changes in:

- An overall sense of wellbeing
- Physical ability
- Skills
- Communication – speaking and expressing needs and emotions
- Living in the world with others – relationships and social life
- Cognitive understanding – making sense of the world and making decisions
- Organisation and structure

Some studies have shown that engagement in creative activity can help people to build a resistance to stressful situations that prevent them dealing with health changes (e.g. Verghese et al., 2003; Moos and Bjorn, 2006). In light of these studies, it can be argued that for people who face significant Parkinson's-related adjustments, the opportunity to engage in creative activities is highly desirable. When these activities simultaneously involve care-givers/family/friends, a whole range of stressful situations may be explored. These observations support the view that, as a creative and social activity, singing regularly in a social environment could help people living with Parkinson's and those closest to them to explore ways in which they deal with the inevitable life changes.

## The current national policy framework for the care of people with Parkinson's

Amongst other conditions such as multiple sclerosis, motor neuron disease and cerebral palsy, Parkinson's is listed by the Department of Health as a Long-term Neurological Condition (LNC). Since the beginning of the twenty-first century, UK Governments have produced a number of policy documents that aim to improve quality of life for people living with long term conditions of this type (e.g. DH 2004; 2005a; 2005b; 2008). Recommendations include reducing stigma, social exclusion and discrimination, and improving services from diagnosis to end-of-life care. An overarching characteristic of these documents is an emphasis on helping people to live independently for as long as possible.

Currently a range of health professionals and support workers help people living with Parkinson's. This includes on-going clinical support from family doctors, neurologists, specialist nurses, physiotherapists, occupational and speech and language therapists, social workers, pharmacists and dieticians (Aragon et al., 2007). In addition, the charity, Parkinson's UK, contributes to Government policy and provides a wide range of information services and support for people living with Parkinson's and their care-givers. The charity is currently championing the country-wide development of Parkinson's nurse specialists (PNSs). The present small number of PNSs are liaising with professional and voluntary organisations to lobby for the development of a comprehensive service ensuring ongoing, joined-up care (Parkinson's UK, undated b). They also work directly with people living with Parkinson's and their families. Part of the role of PNSs is to identify services that best suit each individual's circumstances bearing in mind their unique experiences of living with Parkinson's.

## How group singing can support people affected by Parkinson's

Group singing can help support people who are facing a range of challenges arising from Parkinson's.

**An overall sense of wellbeing:** A sense of wellbeing is significantly affected by people's view of their physical, psychological and social statuses. A feeling that these are increasingly in jeopardy can result in a severe sense of ill-being. Being active in a singing group vocally and physically; having musical goals; feeling valued as a member of the group; being with mutually supportive people who have an understanding of the challenges faced; and engaging in creative activities are known to stimulate positive hormones that can all help to counter some of the challenges arising from living with Parkinson's.

**Communication:** Singing can help people with Parkinson's communicate in a number of ways. Firstly, the physical act of singing can reflect the well-established principles of the Lee Silverman Voice Treatment for people with Parkinson's (see above). Secondly, singing provides opportunities for people to express/explore/reflect on their emotions. Particularly challenging issues that people are facing can be highlighted and their importance acknowledged by channelling them into familiar or newly composed song lyrics and tunes. Thirdly, improvised activities can stimulate immediate, here-and-now communication that is not dependent on memory. This is particularly important for people who have Parkinson's dementia. All of these activities can elicit a sense of expectation, achievement and hope.

**Cognition and understanding:** Two of the most fundamental human needs are the capacity to understand and to be understood. Some level of participation in singing in social groups is arguably accessible to everybody regardless of their understanding of the world. Sharing rhythms, melodies and harmonies and memorising and/or repeating words can demonstrate an understanding between participants. Accessing tunes, singing, humming familiar songs, swaying or moving rhythmically, connecting with familiar musical sounds, such as the major scale, appear to be independent of higher cognitive function.

**Living in the world with others:** There is plenty of evidence to show the beneficial social effect of singing in groups. This can be capitalised upon through activities that include group cooperation, such as democratic choices, turn-taking or small-group singing. In addition to new relationship-forming opportunities singing together can significantly enhance relationships between care-givers and their cared-for. This can help to alleviate some of the tensions that occur between people who have together to face the challenges associated with Parkinson's.

**Organisation and structure:** For people affected by Parkinson's, a sense of organisation and structure may be seriously disrupted for all sorts of reasons. Meeting regularly with the same group of people at the same venue and time of the week can create an important anchor. In addition, the songs used in singing groups tend to be structured forms that are easy to access and not necessarily dependent on any specific level of cognitive function. A systematic way of developing singing technique and repertoire as the sessions proceed can also elicit a sense of organisation and structure.

**Skills:** People with Parkinson's and their carers usually have to face loss of skills as the condition progresses. Attending singing groups can provide participants with opportunities to use retained skills and to develop new skills. The individual skills of participants should be acknowledged and utilised where appropriate. This may include opportunities to help with: planning and session practicalities; suggestions/help with repertoire; leading or contributing to an activity in some way; practical, social and/or emotional support for others in the group. In terms of learning new musical material, as with all singing groups, participants will learn at different rates, so those who absorb new learning quicker can help to support others.

**Physical ability:** The mechanical processes of singing can help to support physical function in people with Parkinson's. These include muscular exercises to promote facial, throat and chest muscle mobility and vocal clarity, strength and production; deep-breathing to encourage improved lung capacity; and postural exercises, encouraging improved stability on standing and regulating walking pace. Singing activities may generally help to counter the consequences of diminishing mobility so commonly experienced by people with Parkinson's. When shared as a communal activity in singing groups, physical actions can engender a sense of belonging and bonding.



# Evidence

## Case studies

Case studies provide the most abundant evidence of the value of group singing for wellbeing. Across the UK a growing number of singing groups have been established for people affected by Parkinson's. Some have run for several years. The commitment of participants and numerous anecdotes about the benefits are testament to their perceived value (e.g. Magee et al., undated). Members of the Sidney De Haan Research Centre are currently undertaking formal research looking at the processes and outcomes but the following case studies provide an overarching picture.

### Sing for Joy (London)

Sing for Joy members meet once a week on Tuesday evenings in Kentish Town, London. The group was initially formed through the endeavours of Nina Temple who was diagnosed with Parkinson's at the age of 44. Current Sing for Joy leader, Carol Grimes, uses a holistic approach to support people's physical, emotional, mental and social sense of wellbeing. The group's repertoire includes a wide range of musical genres and world music. Preparation and taking part in performances are important aspects. So far the group has performed in venues such as the Southwark Cathedral and the TUC Congress Hall and they have given an open workshop at National Hospital for Neurology and Neurosurgery in Queen Square, London. (Magee et al., undated). To raise awareness of Parkinson's on a larger scale, the group recently gave two performances at London St Pancras station next to the statue of John Betjeman, who also had Parkinson's (see [www.bbc.co.uk/news/uk-england-london-18193522](http://www.bbc.co.uk/news/uk-england-london-18193522)).





### Quivers and Quavers (Hereford)

Quivers and Quavers members meet fortnightly in a sports hall in Hereford. The activity is described as 'an innovative voice therapy group for people with Parkinson's' (McColl, 2008). The main goal of the activities is to improve or maintain vocal health and enhance quality of life through the social benefits that a shared activity promotes. The project was founded by Mike Canavan, who hoped that singing activities would support his, and others' Parkinson's-induced speech and communication problems. Current leader, singing teacher and opera singer, Roger Langford, describes the activities as 'humorous, relaxed and challenging' with an emphasis on improving the four main parameters of speech which are commonly jeopardised in Parkinson's: respiration; phonation (vocal sounds, for example, articulation); movement of facial muscular apparatus. The group's activities have prompted several news articles, a report for Hereford Primary Care Trust and a published academic paper on the impact of singing on these functions (McColl, 2008; Evans et al., 2012).



### Start the Week with a Song, Christchurch Hospital (Dorset)

Start the Week with a Song was initiated by Coda Music Trust in 2010 through collaboration with Dorset PUK and the Speech and Language Team at Christchurch Hospital, Dorset. The initiative is described as vocal therapy for people living with Parkinson's and other neurological conditions, such as stroke. The current ongoing activities were motivated by evaluation of a trial pilot project. The evaluation centred on speech and language issues and showed an improvement in maintaining vocal strength and control at the end of ten-weekly sessions as well as improved confidence and well-being among participants.

The results have encouraged participation which has enabled Coda to continue to run regular weekly sessions on a Monday, charging £3 per participant. The current sessions are run by music therapist, Susan Nares and engage between 15 and 25 participants. Each session includes specific breathing, posture, vocal and relaxation exercises, which are addressed in various creative ways for the group as well as moments to touch on person centred needs with the therapist and other members of the group. A volunteer supports the session and partners are welcomed.

## Skylarks (Canterbury)

The Skylarks Singing Group meet fortnightly in a local Age Concern day centre in Canterbury. The group was established in February 2010 by Roger Clayton, who was diagnosed with Parkinson's in 2006. Roger was inspired after hearing talks by Nina Temple (Sing for Joy) and Roger Langford (Quivers and Quavers). Skylarks is led by Grenville Hancox, Professor of Music, Canterbury Christ Church University. Grenville and Roger have kept detailed blogs in which they describe setting up and running the singing group. The following extract shows how the group was conceived and set up and illustrates the personal impact on Roger and some of the other participants who took part.



Jill Clohessy, Skylark singer, describes the benefits of singing:

"I've always liked singing, and before I had Parkinson's I sang a lot in school choirs etc. Since getting Parkinson's my voice has gone flat. However I watched a TV series about a Community Choir being led by Gareth Malone which inspired me. I then saw in the Parkinson's magazine that the Canterbury branch had started a choir, made contact and came along here. I really love coming to Skylarks."

"It has made a lot of difference to my mental health; it has not been a good day today, with a lot of shaking, but I have cheered up enormously at the thought of singing with Skylarks. My husband says I sometimes get hyper after a singing session. I really like coming."





## Sylarks Blog by founder member, Roger Clayton

24 November 2009

I go to an excellent seminar at the Sidney de Haan Centre for Arts and Health, where the leaders of two singing groups (Herefordshire and North London) explained how and why they ran Singing Groups for PWP [people with Parkinson's] and told of the benefits. Grenville Hancox (GRH), Director of Music at Canterbury Christ Church University and a close friend of mine, agreed to lead a Singing Group for PWP in Canterbury, if I could organise it.

4 December 2009

The Canterbury branch of Parkinson's UK warmly endorses the proposal and we decide to call it 'Skylarks'.

6 January 2010

Canterbury [Parkinson's UK] branch New year's lunch: I speak to the diners before the start of the meal about the new Singing Group. I then thought I should

talk individually to each diner; this proved to be very useful as many said "Nice idea, but I won't come as my voice is fading because of Parkinson's". I reply "that is EXACTLY why you should come as singing will strengthen your voice - and anyway you will enjoy singing".

I make a list of people interested and it totals 35! (out of 55).

I make arrangements with Age Concern for the venue and agree dates with GRH.

The Kentish Gazette kindly places an article for me about the first session of the Skylarks.

6 January 2010

I give a brief talk about Parkinson's and the activities of the local groups to the Canterbury Sunrise Rotary Club. They very generously decide to give the local branch a donation of £1,200 in 2010 and the same amount in 2011. This will be an enormous help.

23 February 2010

First session! How many will turn up? I guess about 20; will be very pleased with 25, and disappointed with 15 or less. I collect spare chairs from Fordwich Town Hall and set up the room with chairs in an arc - I hope GRH approves of the layout.

Then I wait.

35 people come!  
I'm over the moon!

GRH leads Skylarks brilliantly, striking just the right note. He gets us singing immediately and everyone seems to be enjoying

themselves. Happy buzz at the interval. Second half goes equally well. I am delighted when GRH gives Sarah Hale, voice coach and speech therapy assistant, a slot - she is good and enthusiastic.

Sue (my wife) takes lots of photos which come out well; the best one is sent to a couple of our sponsors, the Canterbury Rotary Sunrise Club and the Streynshams Trust.

Everyone (including me) leaves on a high!

25 February 2010

GRH forwards me the following:

"My Mum was diagnosed with Parkinson's eight years ago and suffers from acute anxiety, especially in public situations. To say the singing group was a triumph would be an ENORMOUS understatement. It was the first time she has felt comfortable enough to stay for an entire group event in a very long time. She was literally buzzing on the way home, as was I."

Daughter of PWP, Canterbury Singing Group, 23 February 2010

It sums up why I am so keen that Skylarks flourishes.

## Research evidence on singing and Parkinson's

A growing body of research has shown the value of singing in supporting a sense of health and well-being relating to: physical wellbeing, such as perceived improvement in lung capacity and/or posture (Clift et al., 2008); emotional well-being and mood-regulation associated with the release of mood-related hormones (Sloboda and Juslin, 2001; Grape et al., 2003; Beck et al., 2000; Kreutz et al., 2004; Davidson, 2004); social wellbeing, such as sense of belonging and/or being part of a creative process (Clift and Hancox, 2001 and 2010; Clift and Morrison, 2010; Clift et al., 2007 and 2010).

A number of studies have shown that group singing may help with a range of complex functions directly relevant to people living with Parkinson's. For example, a study that evaluated the effects of a music and singing therapy programme shows improvements in general motor function (Pacchetti et al., 2000). Other studies have also shown that singing may help to regulate walking pace and length of stride, and so help to guard against falls (Bower et al., 1999; Howe et al., 2003; Elston et al., 2010). This is because the act of singing stimulates multiple areas of the brain and impacts on the loop of information that feeds back and forth from the auditory (hearing) system and the sensory-motor systems (Kleber et al., 2009). In this case, songs with a strong musical rhythm may be of value.

Basic vocal warm-up exercises can help to improve diaphragm and chest extension, and, therefore, improve breath-depth and stability of posture (Wiens et al., 1999; Gotell et al., 2003; Bonilha et al., 2009). Studies on the effect of singing to improve speech for people with Parkinson's have shown significant improvements in voice production (Baumgartner et al., 2001; Evans et al., 2012). Rhythmic chanting and singing can help to improve loudness and prevent slurring by supporting chest, throat, mouth and facial muscle-mobility. It can also help with other speech problems, such as stuttering, by stimulating motor regions in the brain that are involved in fluent articulation (Haneishi, 2001; Di Benedetto et al., 2008; Wan, 2009).

In addition to improving communication and mobility, singing may help to alleviate some of the emotional difficulties associated with Parkinson's. This may be undertaken as a formal Music Therapy (MT) intervention in a clinical setting. Research on one such intervention, in which singing was used in a programme for people with Parkinson's, showed significant improvements in their emotional wellbeing throughout the duration of the programme (Pacchetti et al., 2000). This may, in part, be accounted for by the release of hormones, such as cortisol and oxytocin, and immune-system props, such as Immunoglobulin A, which are known to occur during group and solo singing (Beck et al., 2000; Grape et al., 2003; Kreutz et al., 2004). These hormones are collectively associated with life-factors that are often negatively affected by Parkinson's. These include mood-regulation, a sense of self-esteem and self-confidence, sleep patterns, memory and new learning, social bonding and trust, and anxiety (Parkinson's UK, undated a).

In terms of psycho-social well-being, the changes that Parkinson's brings can seriously jeopardize an individual's sense of personal identity and social belonging. Taking part in a group creative process can elicit a sense of worth and purpose. When this process involves singing in an environment where difficulties with vocal and physical ability are met with understanding and empathy, individuals may be enabled to better acknowledge and express their associated emotions, their sense of self and their relationships with other people (Pacchetti et al., 2000; Hays and Minichiello, 2005).

A further and critical factor to be aware of is the support that group singing can bring to people caring for those living with Parkinson's. It is known that carers, particularly those caring for frail older people, are highly susceptible to stress. Unsupported, this can significantly affect carers' ability to care and can lead to long-term carer ill-health and premature admission into residential care for their loved-ones (Carers UK, 2005). The relationship between people living with Parkinson's and their carers is a key factor in both party's ability to cope through the changing condition. Singing together in activities that are fun, stimulating, motivating and appropriately challenging can enable a sense of shared achievement and emotional expression. This can have a positive effect on carer/cared-for relationships and support a mutual sense of well-being (Davidson and Faulkner, 2010).

# Practice

## Guidance on setting up and running singing groups for people affected by Parkinson's

In addition to keeping a week-by-week blog, Roger Clayton has provided useful guidance on how to approach setting up singing groups for people with Parkinson's. The following highlights Roger's key considerations.

### Finding a local champion

It is helpful if the local Parkinson's branch can select a member to take responsibility for promoting and running the Singing Group. The responsibilities of that person include, promotion, liaison with the singing leader, publicity and organising the sessions.

### Promotion

Promoting the concept of a singing group is important. This may include providing information for:

- The Parkinson's branch newsletter
- The Parkinson's branch meetings
- The local press
- Local specialist Parkinson's nurses
- Local speech therapists
- Parkinson's branch members (talking to individuals)

### Singing leader/facilitator

The recruitment of the singing leader is the most important factor in the successful launch and continuation of a singing group. The qualities to be looked for include:

- Experience of leading a singing group
- Knowledge of the type of exercises which will strengthen vocal muscles etc.
- Personal charisma to enthuse the singers

### Practical arrangements for the sessions

- Frequency: the commonest pattern is once every two weeks
- Duration: many groups find that each session should last about 105 minutes, with a drink break half way through.

### Venue considerations

- Car-parking
- Disabled access
- Availability of toilets
- Availability of water to drink
- Flat space
- Upright chairs (better for singing posture than lounge chairs)

## Finance

- Charges: some branches charge a fee of £3 per session
- Budget: a typical budget for a singing group
- Fund-raising: setting up a singing group seems to appeal to a range of local charitable organisations e.g. Rotary, Lions, Inner Wheel

## The facilitator

As highlighted by Roger Clayton, the role of the facilitator is fundamental to the group flourishing. The facilitator of a singing group for people living with Parkinson's ideally needs to be:

- Musically skilled
- Socially skilled/receptive
- Sensitive to the specific needs, circumstances and capacities of individuals
- Knowledgeable about the specific health condition
- Organised
- Creative
- Flexible
- Humble

Prospective facilitators may not always possess all of these ideal skills and qualities. Some may feel in need of training in one or more areas. It may be possible to contact organisations/projects/individuals with relevant experience to explore the feasibility of arranging mentoring or training. Some ideas of organisations are given in the resource section of this guide.

## The delivery approach

Every facilitator will have their own unique way of working with their groups. This will depend largely on their personality, training and experience. Some core aspects of delivery are desirable in all singing groups but facilitators may approach them differently. When facilitating singing groups for people living with the effects of Parkinson's, facilitators might consider:

- What individuals hope to get out of the sessions (e.g. social support; respite; recreation; singing tuition)
- The mobility and comfort of singers and how to organise practical aspects of sessions appropriately (e.g. timing; duration; seating; breaks; access to toilets; safety; design of song sheets, if used)
- The range of singing experiences of individuals in the group
- How to respect the group musically
- How to protect uninitiated voices and develop the collective voices appropriately
- The musical balance/pace of each session, for example repertoire variation/familiar material vs. new teaching
- Varied approaches to teaching new material
- Mechanisms for progress and goals most appropriate for the group
- Whether or not to open the group to people living with other neurological conditions such as stroke or cerebral palsy
- Supporting care-givers and their cared-for as the latter's condition changes
- Supporting care-givers who no longer care full-time



## The repertoire

Facilitators of any singing group will inevitably have material that he or she feels is appropriate for the group and is most comfortable teaching. However, it is probably best to keep a flexible approach as to how the repertoire will develop over time. Successful repertoire development will depend on the facilitator's understanding of material. This includes its social relevance variation, level of challenge and flexibility

Preconceptions about social relevance of musical material can potentially impose limitations on the group. A group may develop a collective liking for particular genres, such as songs from shows, hymns, spirituals, Rock 'n Roll or pop songs, but it is equally common for individuals in a group to have their own varied tastes. If care is taken to also elicit the opinions of singers who may be less vocal in the group, a repertoire can develop over time that is uniquely relevant to the group. The facilitator's input should include suggesting and arranging songs to suit the group's ability and choosing material to develop specific social/vocal dimensions, as appropriate.

In specifically designed repertoires, it may be appropriate to include music from across the world. For example, a Nepalese lullaby may help the group to develop certain vocal techniques, or an African call-and-response chant may encourage social interaction. New material such as this should be accessible at some level to everyone in the group: in other words it needs to be flexible. For example, words may be dispensed with, short sections of the song may be repeated (as in doubling a chorus) and the speed and/or pitch may be altered.

Facilitator flexibility is important in all singing groups but perhaps particularly in groups of people affected by Parkinson's because of the progressive nature of the condition. The level of challenge needs to be regularly reassessed. It is likely that some singers' ability to access new material will differ over time and where once singers may have enjoyed singing in canon, the complexity of sound may become overwhelming. It is incumbent on the facilitator to assess such changes and address them appropriately.

## An example of repertoire

The following extract is taken from session notes written by Skylarks' facilitator, Professor Grenville Hancox. It provides insight into development of repertoire from the facilitator's perspective.

### Skylarks Session 9 November 2010

#### Warm ups:

*Tip of the tongue*  
*Together with friends*  
*Sol fah*

"What a great session this was today. The singing was excellent and the determination to improve, to find a collective spirit, and in so doing to support each other, was tangible. I began with some warm ups. Silly little ideas that allow the group to make as much sound as they like without fear of embarrassment. Thus the sipping in of air, holding and exhaling for four, eight and twelve counts, cements each week the notion of diaphragm support. This was followed by a moan to each other.



Tonic sol-fah next. Revision of doh, ray, me, soh, lah hand signs and pitches is reassuring. The pitch is good and the sound being produced much stronger than previously. Thus I ask the men to sing an ostinato of doh/soh/doh, which they do with confidence. A small round is based over this.

A pentatonic chord doh, ray, me, soh, lah is sung confidently, repeated a few times and then decided that this should be Skylarks' call sign: doh, ray, me, soh, la x 3, followed by 'Skylarks. We're here!' This was very strong. I needed to be able to record this! We decide to use this call sign for anything we perform.

This was followed by 'Together with Friends' which is learned very quickly. Sing this in a round of three parts, the parts of equal strength and holding pitch well. Calypso follows, with accompaniment.

Introduced 'While Shepherds Watched' to tune of 'Ilkley Moor Bar Tat'. This for the carol service on 14 December and to the famous tune written by a Mr Clarke from Canterbury. We have developed this by having ladies and gents separated and treating it as a call and response song. This allows for real harmony to be felt and appreciated.

Carol for the Huron Indians. Revised and harmonies added at beginning and end of each verse. It is sounding very well and will have some percussion added for the performance on 14th December.

'Five Foot Two Eyes of Blue'. Sung with great enthusiasm and when I asked if anyone could dance the Charlestone, John offered and danced with gusto; so too Roger. This was amazing as John came to the session not looking well indeed being helped to his seat by his helper. Four weeks ago he left hospital. The two dancers captured the essential spirit and character of this remarkable group of people. We are here! Watch out!

Finally we rehearsed once more 'While Shepherds Watched', gentlemen responding in harmony to the ladies."

To sum up, the principles that underpin high standard, professional leadership centre on the facilitator's ability to empathetically and appropriately conceive the programme and to deliver it in an efficient, kind and supportive manner.

## Guidance on monitoring and evaluation

In setting up a new singing group for people affected by Parkinson's, it is important to consider the issue of monitoring and evaluation from the outset. Indeed, this may be a pre-requisite of funding in some cases. Gathering evidence on the process of outcomes of any project which aims to improve wellbeing and health is also essential to check whether the activity is having the desired effects.

Good quality evaluation is challenging and time-consuming. Where possible the assistance of an external evaluator is ideal – not least because it gives some assurance of the independence and objectivity of the evidence gathered.

There are many approaches to evaluation, some simple and others more complex, and a wide range of methods can be used to gather information. It is important to explore the options, particularly for people who may have difficulty expressing themselves verbally or in writing. In the case of people living with Parkinson's, this may be a joint process between them and their care-givers.

### Qualitative monitoring of process and outcomes

The simplest approach to evaluate what happens in singing groups and how this affects participants is to gather information from participants themselves. Simple questionnaires can be used to ascertain participants' experiences during the singing sessions and what they feel they gain from their involvement. For this purpose structured questions, which have short tick-box answers, can be used in conjunction with space for people to write their own comments.

### Use of structured pre-validated questionnaires

A further step is to attempt to measure outcomes from participation in singing groups using previously published questionnaires which are the result of a rigorous process of development and validation to show that they give meaningful results. In evaluating the effects of activities for people living with Parkinson's, a number of pre-validated questionnaires are used. These include the well-established Unified Parkinson's Disease Rating Scale (UPDRS), which is the most commonly used questionnaire to assess mental functioning, motor skills and the affects of Parkinson's on activities of daily living (Fahn and Elton, 1987). The PDQ-39 and PDQUALIF questionnaires are used to assess the stage of the condition and quality of life issues. The earlier Hoehn and Yahr and Schwab and England rating scales also measure the stage of the condition and level of disability respectively (Welsh et al., 2003).

### Controlled experiments on the effects of singing

The second approach to evaluation has the merit of attempting to measure change with a validated questionnaire. It has the obvious weakness however that the changes observed could have happened anyway or as a result of many other influences in people's lives in addition to being part of a singing group. For this reason, some kind of 'control' group is often recommended in evaluations of a project to provide a point of comparison.

The strongest form of controlled experiment is referred to as a randomised control trial (RCT). A control group would be established at the same time as the experimental singing group and participants would be randomly assigned to either one. The control group would be asked either to engage in their normal life activities or in an alternative activity set up specifically for the study whilst the experimental group engage in singing activities. Skingley, Clift, Coulton and Rodriguez (2011) present a protocol for a controlled study which aimed to assess the effects of group singing on the mental wellbeing of people aged 60+. The authors observe that whilst robust in design, RCTs are challenging to set up because they are costly (e.g. twice the number of interventions; experimental and control) and time-consuming to plan.

A small number of previous studies on the effects of music on people living with Parkinson's have used a control group but the numbers are often too small to draw definitive conclusions. This indicates the need for more robust research in this area.

## Research ethics

When planning a research study with people who may be vulnerable it is important to understand the principles of research ethics. For example, informed consent confidentiality and data protection. Where an external evaluator is involved they will need to seek ethical approval from an appropriate body, for example a local research ethics committee. Establishing sound ethical principles not only ensures protection for participants but it is usually a pre-requisite for publishing research findings in a respected, professional journal. Such publications are highly desirable because they formally add weight to evidence of value and they are likely to support future funding applications.

## Sources of support and funding

There is increasing interest across the UK in the idea that singing can be beneficial for wellbeing for everyone, including people living with progressive and enduring health problems. Organisations and individuals with experience in this area are available to give help and support to anyone interested in setting up new groups, and details can be found in the resources section in this guide.

Funding is also a perennial challenge, although the costs involved in setting up and running a group are not very great. Funds are needed for the facilitators fee (and perhaps an accompanist or a system to play backing tracks), a venue and song sheets. Music practitioners should liaise with Parkinson's-focused charities and support services to discuss practical possibilities and sources of support. Local NHS trusts and local commissioning consortia can also be approached to explore sources of funding. For more ambitious projects, funders such as the Big Lottery and other charities with an interest in the arts could be approached. There may also be opportunities for private or corporate sponsorship from individuals/companies known to have a relevant interest.

The voluntary organisation Funding Buddies, is currently able to offer help with identifying sources of funding and a mentor scheme for bid-writing. They also offer a written toolkit (for Kent see [www.fundingbuddiesinkent.org.uk](http://www.fundingbuddiesinkent.org.uk)).

The introduction of personalised budgets for social care may also be a source of funding for individuals to engage in singing for health groups, if participants provide some of their budget to pay for such an activity.

# Resources

## Parkinson's UK

Parkinson's UK (formally Parkinson's Disease Society) is a support and research charity that has been in existence for over 40 years. In addition to a confidential online helpline, the charity provides services for people with Parkinson's across the UK at a local level. It also provides a wide range of training and education for health professionals. In terms of research, the charity funds important projects on the cause of the condition, bio-markers, the process of nerve cell death and treatments and therapies.

Parkinson's UK web site: [www.parkinsons.org.uk](http://www.parkinsons.org.uk) Online helpline, email: [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

## Singing and people with Parkinson's

Sing for Joy, Kentish Town (London): For information visit: [www.carolgrimes.com](http://www.carolgrimes.com)

Quivers and Quavers, Hereford (Herefordshire):

For information contact: Mike Canavan, Well Cottage, Common Hill, Fownhope Herefordshire, HR1 4QA  
Tel: 01432 860983 email: [mikecanavan@onetel.net](mailto:mikecanavan@onetel.net)

Start the Week with a Song, Christ Church (Dorset):

For information contact: Coda Music Trust, Chewton Farm Road, Walkford, Christchurch, Dorset BH23 5QL  
Tel: 01425 276 161 [www.coda.org](http://www.coda.org)

Lanarkshire and Glasgow PUK Singing Group (Glasgow, Scotland):

For information visit: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

## Music organisations for support and training

Natural Voice Practitioners Network: The Natural Voice Practitioners' Network is an organisation for Practitioners who share a common ethos and approach to voice work. NVPN believes that singing is everyone's birthright and they are committed to teaching styles that are accepting and inclusive of all, regardless of musical experience and ability. [www.naturalvoice.net](http://www.naturalvoice.net)

Nordoff Robbins: Nordoff Robbins is a national charity that focuses on music therapy to support the lives of children and adults across the UK. The organisation also provides one-off or short programmes on developing musical skills and help with working with community groups. [www.nordoff-robbins.org.uk](http://www.nordoff-robbins.org.uk)

Sense of Sound: Sense of Sound's mission is to always be at the forefront of vocal education and to provide training, employment and promotional opportunities at the highest level in the creative industries for singers and songwriters across the UK and internationally. Sense of Sound delivers high-quality inclusive vocal training, develops and nurtures aspiring singers. [www.senseofsound.org](http://www.senseofsound.org)

Sound Sense: Sound Sense is a membership organisation that provides support to organisations and individuals who help people make music in their communities through leading music workshops and teaching. [www.soundsense.org](http://www.soundsense.org)

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