



AWAKENING YOUR VOICE

Parkinson's and Singing

Nicola Wydenbach

To observe how other countries approach Parkinson's and singing

by watching and participating in three Tremble Clef Groups in California

23rd-31st October 2014

Supported by the Finzi Trust Scholarship

In my case, though, Parkinson's has also granted one of my keenest desires. After decades of hopelessly wishing on birthday candles and turkey collarbones that I could carry a tune, suddenly I can unashamedly join in family singalongs. I can sing.¹
Phyllis Richman

¹ Singing allows people with Parkinson's disease to exercise their vocal chords;
http://www.washingtonpost.com/national/health-science/singing-allows-people-with-parkinsons-disease-to-exercise-their-vocal-cords/2012/04/02/gIQADtYMrS_story.html

OUTLINE OF ITINERARY

Depart 23 October BA0283 09.40 Heathrow

Land 23 October 12.45 Los Angeles

Transfer to Accommodation

Accommodation Dana Point Condo 34371 Dana Strand Rd 1 Dana Point CA 92629

Monday 27th October

First Visit to Tremble Clefs Laguna Woods 9.30 – 11.00

Florence Sylvester Senior Center 23721 Moulton Pkwy, Laguna Hills, CA 92653

Contact Karen Skipper kmsmusic@cox.net

Tuesday 28th October

Second Trip to Tremble Clefs San Diego

1-2:30 at 890 Balour Drive, Encinitas, CA.

Contact Kathleen <http://kathleen@sandiegomusiccoach.com>

Wednesday 29th October

Meeting with Michael Chesebro Speech Therapist

Hospital San Pedro

mechesebro@juno.com

(Unfortunately after setting up a meeting, Michael did not confirm however, I have worked with British Speech Therapists)

Thursday 30th October

Third Trip to Tremble Clefs

This includes a visit to a dance group as well as a singing group.

12.00 Tremble Toes

1.00-3.00 Singing Group

khesley@hotmail.com

Depart Thursday 30th October 21.45 BA0268 LAX

Land Friday 31st October 14.55 Heathrow

INTRODUCTION

As an amateur and singer with over ten years experience of working with many different types of singing groups including the homeless, special needs children, special needs adults, school children and community groups to name a few, I have become more and more interested in working with more specific groups including dementia and Parkinson's.

Parkinson's and singing has sparked my interest because not only are there social benefits - a sense of well-being, communication, community, organization and enjoyment, as well as increased confidence - more importantly there are also medical benefits for Parkinson's patients including vocal strengthening and motor skills.

While researching this subject, I came across a group called the Tremble Clefs (<http://www.trembleclefs.com>) who have been working in this area for over twenty years.

The aim of the project was to observe an overseas, established programme. I wanted to see if there was any difference in this kind of work overseas and if there were any practices that could be brought back to help develop similar programmes in the UK

PARKINSON'S DISEASE

What is Parkinson's Disease?

Parkinson's Disease is a neurological disorder that affects the motor system. It is a brain disease that can affect how a person moves. People with Parkinson's can have muscle tremors, slowed movements, rigid muscles, and difficulty with balance and walking. Parkinson's is chronic and it's progressive. Some symptoms of Parkinson's are cognitive too. The same brain changes that affect the motor system also result in slowness in memory and thinking.

How does Parkinson's Disease affect the voice?

Because Parkinson's Disease affects the muscular action and strength, it affects the voice. It can affect volume and produce hoarseness, a breathy quality, monopitch, and imprecise articulation.

Why Parkinson and Singing?

Are all people with Parkinson's doomed to a future of silence? Not at all. For some, singing is exactly what is needed:

- By using singing as a tool, some people with Parkinson's can improve the quality of their breath, which in turn aids with volume and hoarseness.
- The concentration that a professional singer would incorporate when working with consonants in order to project to the back of a theatre will benefit a person with Parkinson's, by helping them to articulate a sentence and still have their voice heard.
- It has been found that people with Parkinson's suffer from a lack of dopamine. This chemical is released when singing.
- The larynx becomes weakened with Parkinson's. As the disease progresses, this weakening can lead to aspiration pneumonia, a common cause of death. The swallow mechanism does not work and instead allows food and liquids into the lungs. Singing exercise, particularly those based round an octave to make the larynx jump up and down, have been found to help.
- Lastly the rhythmical nature of singing can actually help regulate the pace of walking and the length of stride².

So with all this in mind I set off to America to see how an organisation, the Tremble Clefs that had just celebrated their Twentieth Anniversary, put all this into practise.

² Bower et al., 1999; Howe et al., 2003; Elston et al., 2010



The Tremble Clefs began in 1994 after Karen Hesley formed a vocal group as a legacy for patients who have completed the Lee Silver Voice Treatment (LSVT) vocal therapy programme.

Karen is a trained speech therapist. She created the Tremble Clefs so that Parkinson's patients who had completed LSVT still had somewhere to practise their vocal exercises. The Tremble Clefs originated in Phoenix, Arizona and then subsequently opened branches across California.

As it says on the website:

It is a program for people with Parkinson's and their partners. The Tremble Clefs Program establishes singing groups in which individuals share in a joyful activity with therapeutic results and work toward a common goal. Participation in a Tremble Clefs singing program can help address voice and communications problems through breathing, stretching and posture activities, vocal exercise, rhythm and movement, and a strong social support system.³

<https://www.youtube.com/watch?v=09zNy0Ax9w>

<https://www.youtube.com/watch?v=0xXuhLlv8aQ&feature=related>

The Lee Silverman Voice Treatment (LVST) is a rehabilitation programme that assists people with Parkinson's disease.

There are two strands, LVST Loud and LVST BIG

LSVT LOUD - Benefits of LSVT LOUD

- Improved vocal loudness - Speech will become louder, slower and clearer.
- Improved speech intelligibility - Speak more clearly on the phone, in restaurants and other social situations. More facial expression. Improved ability to swallow.

LSVT BIG - Benefits of LSVT BIG

- Helps avoid inactivity
- Increases ability to perform daily activities
- Faster walking with bigger steps
- Better balance
- Increased trunk rotation
- Improved quality of life
- Therapy to increase loudness without damaging vocal cords
- Retraining for more normal "Big" body movements

³ <http://www.trembleclefs.com/index.html>

I had the privilege to watch three groups in California - in Laguna Woods, Encinitas and San Diego. I learnt so much from the inspiration leaders, Karen Skipper, Kathleen and Karen Helsey herself.

Every few years, the groups meet for conferences. They recently had one in May 2014 to celebrate their twenty-year anniversary

Laguna Woods Monday 27 October

Florence Sylvester Memorial Senior Center
23721 Moulton Parkway
Laguna Woods, CA



At 9.30 I observed a group that has been running for ten years, the last four under the leadership of the truly remarkable Karen Skipper. The group was over thirty strong, a mix of people with Parkinson's, carers, relatives and significant others. One lady's husband had passed away a few years previously from Parkinson's but she still came to choir every week because of the friends she had made. There was also an equal mix of men and women. The local Parkinson's association funded the group.

The group were very welcoming and right from the outset they were having a great deal of fun. They started with warm-ups concentrating on breathing, vowels and the articulation of consonants.

See the two movie attachments: Click on the sign to access, and then expand.

Warm Up Video 1



Warm up Video 2



They did a great physical warm up with wagging fingers, in different directions getting faster as the music accelerates. At the request of the group they demonstrated an exercise that really wakes up the face called sun and moon.

Sun and Moon Video



Parkinson's patients' faces often become devoid of emotion and expression and this was a great exercise to counteract that. But that being said, the enjoyment in the room was so great that the smiles and laughter completely disguised many signs of the disease. The feeling in the room will remain with me for a long time and I hope to recreate this in the UK.



The group then proceed to go through the programme for a concert that they were doing later that day based on a Broadway theme. There were solos, choreography and even props.

See two videos of the rehearsal

**Video Sunset Sunrise From
Fiddler on the Roof**



**Video You'll Never Walk
Alone from Carousel**





I was lucky enough to talk to the leader Karen. She has such an easy and funny disposition that radiated throughout the group, a style to be adopted. She said that the two main benefits of joining the Tremble Clefs are the social connections and the motivation to get up and do something. She also believes that although not scientifically proved, there is significant improvement to the speaking voice via singing.

I also spoke to some members of the choir including one of the soloists called Bob. He has been coming to Tremble Clefs for eight years. I asked him why. He replied that he can have fun and forget about Parkinson's for two hours. He also said that before he joined he could hardly talk but now he is singing solos.

I sat next to a lady called Beverley who could no longer speak and had quite advanced Parkinson's. But she sang every note.

A wife of one of the singers and a member of the choir herself told me she liked to come to watch her husband enjoy himself for two hours. She again believed it helped her husband's voice.



I came away with a real bounce in my step but also asking, if I can so clearly see the benefit of this work and the leader and the participants are telling me how much it enhances their lives, how come it is taking such a long time for the medical fraternity to believe in it? The problem is proving the benefits, but how do we show that this work is a necessity in order to secure funding?

Encinitas Tuesday 28th October

St. Andrew's Episcopal Church
890 Balour Drive
Encinitas, CA 92024



On Tuesday I went to see one of the North County groups run by Kathleen Hansen in Encinitas. The group were at the beginning of preparing their Christmas music. Each group prepares four programmes a year and aims to perform it at least three times, at senior centres, residential homes, for veterans etc.

Christmas Video





The group had a very different dynamic than Monday's session. This really made me think about the benefits of different leaders and styles. Kathleen was a great musician and was teaching music from scratch whereas on Monday I was seeing a finished program. She taught the group the music regardless of the fact that she was dealing with people with a progressive disease. She was aiming for the best standard that the group could do.

And here lies the beauty of this work. Music is the leveller; regardless of ability the music is at the core. This session did not appear to be as much fun as Monday as they were at a learning stage. But when the group achieved singing in harmony or a beautiful melody, you could see the pride in their achievement. By the end of the session it really struck me that different leaders have different skills to bring but music is always at the centre of the work. Music with its complicated mix of skills and emotions has such a pull so that it makes people with physical difficulties get out of the house every week.



Kathleen's insight on the work was fascinating. She said it enabled people with a degenerative disease to give back. When they performed and saw the enjoyment of the audience, they had a purpose, which gave them motivation. She again talked about the social benefits and the vocal improvements.

Talking to the group, the companionship and support of the group were the main reasons for attending. Madonna, who I sat next to, had been told she could not sing at high school so had originally started making props for the Tremble Clefs. But now she loved it so much she sang in the shower. She also said that her neurologist had heard an improvement in her speaking voice since she had begun singing two years previously.

Again when talking to the group the improvement with vocal production come up time and time again. I hope that it can be scientifically proven once and for all in the near future. But from my observations, it has been the companionship and camaraderie that seems to be the real reason for people's attending the groups.

San Diego Thursday 30th Oct

Palisades Presbyterian Church
6301 Birchwood Street
San Diego, CA 92120

In San Diego, I had the privilege of watching the creator of the whole Tremble Clefs programme, Karen Helsey, at work. Although it was the day of departure, I was determined to meet Karen. The group meet in San Diego and begin with chair yoga at 11.15. Then some of the group participate in a dance class called Tremble Toes at 12.00 and then more join the music group at 1.00. To start with, I watched the Tremble Toes class.

Again run by Karen, the group learnt dances to the songs that they are learning. They were learning dances to Christmas music.

I was really surprised by the difficulty of the choreographed dance steps especially as the movements of people with Parkinson's become more and more difficult as the disease progresses.



See Dance Video



I then watched and joined in the music session with over 40 participants. Karen did some fantastic warm up focusing on breathing, articulation as well as part songs to promote harmony. Karen and the group did a great rap. This confronted their Parkinson's as well as being very good for the articulation. Karen also taught a new version of *Row, row, row the boat*.



They then started practising the same programme as Kathleen's group on Tuesday. Additionally they also had a violinist and guitarist, which brought a different atmosphere. Karen has a very gentle but direct manner.

See Christmas Carol Video



Karen was great at breaking things down to simplify things but at the same time pushing the participants to achieve more than they thought they could. I noticed how welcoming Karen and the group were to new members. The new recruits were made to feel very included and needed from the beginning. To inspire the newcomers, she told an amazing story about how she and the group performed for Muhammad Ali, at the opening of a Parkinson's centre in his name. He enjoyed the music so much he joined in.

The group was again full of joy and happiness but again looking to achieve a good level in all the songs that they were learning. It also really struck me that the American attitude of positivity works very well in this environment. Can this really be recreated in cynical Britain? I believe so as once you take the risk to join a group such as this, the benefits are so great that you keep coming back.



I talked to Karen about the importance of this work. She emphasised the importance of the break or snack time as they called it. She said a physiologist had visited and reported that the snack time was as important as the singing as this helped forge the sense of community. It was Halloween when I visited so the snack time was an elaborate scene of ghouls and ghosts. The group organised this themselves adding to a sense of purpose.

Again when I talked to the participants, they came because of the fun and music making. In many ways, although Parkinson's was the reason that they joined and there are obvious health benefits, the sense of community that belonging to a choir brings seems to be the most important reason, a sense of belonging that we have lost with modern life.

Comments From and About the Tremble Clefs

"The singing has added many things. It helps the vocal cords but it's fun. And having fun is not always easy with Parkinson's."

".....I'm able to get volume now that I never had before. And it's just a tremendous thing to belong to this group 'cause the people that I've met are so friendly. You not only get the music from it but we also get the atmosphere of belonging to a group where everyone has the same type situation and we feel like it's one big family."

"I'm not a very good singer. That's not the objective. The objective is that it makes friendship. That is what we have now. So, I'm proud of that."

"I enjoy the company. I enjoy the singing. Everybody's so nice. I wouldn't miss it for anything."

WORK IN THE UK

OBSERVING GROUPS

Apart from my travels to America I have also been looking into this work in the UK. I have observed a number of groups, worked with two speech therapists as well as running my own workshops and being asked to be a panellist for the City of London Health and Harmony Day. Although this work was not funded by the Finzi Trust, it is fundamental to my conclusion.

In March, I visited Grenville Hancox and his group in Chelsea called Sing for Parkinson's. They have been running for little over a year with a membership of over thirty. Grenville is a very enthusiastic leader and the group loved the songs that he did. He focused on moving as well as singing to encourage the pathways of the brain to stay open that often shut down with Parkinson's. He also used a guitar, which created a great atmosphere. The feeling of the group was one of friendship and support. The group was for carers and people with Parkinson's.

Since observing this group, I have started to teach one of the members privately as he would like to keep his voice strong before the Parkinson's takes hold. Interestingly though, in lessons although I do tailor the work to the condition, we don't talk about it. He wants to learn to sing and not be reminded of the disease. This aspect comes up time and time again. Music can transcend the condition and people feel themselves again.

In July, I had the privilege of observing the Parkinsongsters in Hastings run by Jane Metcalfe. The group has been running for 4 years and is mainly for people with Parkinson's and their carers although it has recently widened to include singers with other problems. But I wouldn't have been able to tell you who was who, carer, a person with Parkinson's, as it was a wonderful session focusing on singing in preparation for a concert in August. This group demonstrates what is so wonderful about this work. Singing together is such a leveller but also so uplifting and life affirming.

SPEECH THERAPISTS

I have also had the privilege to work with two speech therapists. I wanted to make sure that any vocal warm ups I had in mind for Parkinson's patients would not harm them. To the contrary I found the exact opposite.

In May, I observed Julia Johnson **Clinical Lead Speech and Language therapist (Neurology) at Kings College Hospital**. She is trained in the LSVT vocal technique and had arranged for me to watch two patients with Parkinson's. The first patient was a musician himself so we had a great deal in common. He had had previous vocal therapy sessions. The second patient was at the beginning of the treatment. Julia kept reiterating the importance of hydration in Parkinson's. She advised me to let singers keep drinking through a singing rehearsal. The main focus of the LSVT exercises was to make sustained sounds at a good volume. Jane kept emphasising that she was looking for the quality of the sound at all times. Any unhealthy sounds must be seen by an ENT. In a choir situation, I must look out for the unhealthy sounds. As singers we are always aiming to make good quality sounds.

There were also similarities between the LSVT exercises and singing warm-ups. The second exercise focused in keeping the range. The average adult has over 1.8 octaves and with Parkinson's this drops to 1.3. To monitor this Jane used an orchestra tuner. She made the patient produce sounds from low to high and vice versa. It was not hard to see how singing warm-ups could do the same but in a more fun way.

Jane then monitored the level of the patients' everyday speech to see if there was any decline from the previous session. They read prose and poetry and worked on everyday words, emphasising clarity and volume.

Jane was also very enthusiastic about singing for Parkinson's patients. LSVT and vocal therapy is offered for a short intensive period with six monthly check ups. She found that people did not practise in between session. She believed quite strongly that a regular singing group would keep up the work of the vocal therapy course but without it feeling like a chore. She had been an exponent of the benefits of singing for thirty years.

I also observed another LSVT trained speech therapist Suzanne Bennet, a member of the Community Team at Lewisham Hospital. This time we travelled to a patient's home called Janet. She was having her last session in the intensive vocal course. The exercises and approach were very similar to Julia's and it could easily be seen that a regular choir session would have kept up the progress that this lady had made. Also she was very teary and down about her condition. I could not help thinking how a choir would keep up the benefits of the vocal exercise work as well as offering support and a sense of community by being with people in a similar situation.

I hope that in the future there might be chance for music facilitators and Speech Therapists to share their ideas and train together to offer the best practise for people with Parkinson's.

RUNNING GROUPS

I have had the privilege of working with some Parkinson's groups myself in Lewisham and Chatham. In addition, I have been asked to help set up a group in Bury St Edmunds and give a talk to the Guildford Branch of Parkinson's UK. Since winning the Finzi scholarship, I have also been collaborating with the Sidney De Haan Research Centre for Arts and Health.

<https://www.canterbury.ac.uk/Research/Centres/SDHR/Home.aspx>

There is definitely a real interest in the Parkinson's community about the benefits of singing for people with Parkinson's and their carers but unfortunately the lack of funding is a problem. Hopefully, this will change as the benefits of supporting singing for Parkinson's patients are seen to outweigh the costs.

IN CONCLUSION

I would like to thank the Trustees at the Finzi trust for enabling me to go to California and observe three different vocal leaders working with singing and Parkinson as well as being able to talk to participants themselves about the value of this work.

And there it is. The value of this work. I knew before I visited that there were physical benefits, enhancing the voice, helping with hoarseness, breathing as well as releasing dopamine and helping with motor skills due to the rhythms in music. I have also worked with speech therapists in the UK who showed me exercises that could so easily be converted into singing warm up. I have seen first hand the benefits of this work when visiting groups in the UK.

My trip to America confirmed all my previous observations and research, as I was able to see how an organisation that had been established over twenty years worked and how it has survived and developed to where it is today. Many of the approaches to the work that I have seen are similar in the UK and USA. What made observing the Tremble Clefs in the USA so worthwhile is the nature of the organisation in the USA. Throughout my report, it is the sense of community and pride in the work, a feeling of having a purpose that seems to be the reason why the participants keep going back to their singing sessions each week. The Tremble Clefs are not just one singing leader and group working in isolation. The groups are part of something bigger.

There is such good work going on in the UK in this field. I have observed some brilliant groups but they are all working in isolation. Would it not be great if they retained their independence but formed alliances and connections with other Parkinson singing groups? Could you imagine a conference like the one that they recently held in the USA? To create an umbrella organisation to enhance the sense of belonging would be an ultimate goal.

My other conclusion is that this work is so necessary. Proving the scientific benefits will always be a difficult process but I defy anyone to go to session and not feel the impact. I have observed many rehearsals and have always come away with a sense of fun and joy. It also is very apparent that although Parkinson's is the reason why the participants have come together they actually don't want to be reminded of it. They don't want to have it pointed out every time that you do a beneficial exercise to Parkinson's. They want to enjoy the music and have fun. Therefore, it is the job of the leader to incorporate the benefits into the exercise, keeping fun and music at the core.

My aim before America was to set up my own group. But, thanks to my experiences in America and here in the UK, I have realised that instead I would like to train leaders so that more than one extra group can be added to this wonderful work. I plan to raise funds to create a starter pack so that the good of this work can keep on spreading. I would then like to help train leaders all over the country to set up and

maintain their own groups. I would also like to help establish an umbrella organisation. I feel that this large structure would help with the funding issues. Strength in numbers can only encourage funders to support this wonderful and necessary work.

My plans for 2015 include a Residency at Aldeburgh in February to work with local people with Parkinson's and their carers to develop good working practise for singing groups as well as working towards developing supporting material for new potential leaders in this field.

People with Parkinson's still have a voice and we need to help them have their voices heard. After all they still have something to say. So to end this report the words of one of their members sums up this work and why it is so badly needed.

*"The Tremble Clefs has provided companionship and friendship, and also continuity of purpose. It has also given me confidence to be able to speak more."*⁴

⁴ <http://www.trembleclefs.com/comments.htm>

BIBLIOGRAPHY

Books

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Gary Ansdell

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www.parkinsonorg.uk

BIOGRAPHY



Nicola Wydenbach, soprano, is a graduate of the Royal College of Music. Supported by a scholarship from Diva Opera she completed her Graduate Diploma.

She is an experienced educationalist. She is regular leader for Streetwise Opera who work within the homeless sector. She has also been a mentor for the BBC on their project Go Sing!, which encouraged the setting up and running of choirs in primary schools in Westminster. She has also recently been Musical Director for Aldeburgh Festival's pop up performances "Albert Herring Feasts" as well as Gylndebourne's Young Voices Project. She has worked on projects for the English National Opera, Opera North, English Touring Opera, Sing Up and Youth Music. Between 2012 and 2014, Nicola was Vocal Director for Voices of the Future for the Royal Opera House working with schools and teachers in Thurrock to promote singing. This programme is continuing into 2015. She also independently co-runs twice monthly workshops in a ladies hostel in Victoria. Since October 2014, she has been running a choir for mental health on behalf of the Sidney De Haan Research Centre for Arts a Health.

www.nicolawydenbach.com

www.nicolawydenbach.wordpress.com