

Singing, Wellbeing and Health:
context, evidence and practice

Singing and people with Dementia

Trish Vella-Burrows







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

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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 dementia. It also gives examples of setting up singing groups for people living in the community who are affected by dementia. 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 groups of people who live with the effects of dementia and who sing in established, dementia-focused singing groups. It also draws on the experience of music practitioners and health researchers in the Sydney De Haan Research Centre for Arts and Health who have contributed significantly to the growing body of evidence and who have helped to establish singing groups for people with specific health conditions, including those affected by dementia.

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 dementia. 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 dementia 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 dementia
- Family, relatives and friends of people with dementia 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 living with dementia

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 dementia in the UK

The term 'dementia' is a generic description for various complex syndromes which adversely affect the function of the brain. Currently, around 820,000 people in the UK have a diagnosis of dementia. The estimated cost of care and lost productivity is £23 billion (Luengo-Fernandez, Leal and Gray, 2010).

The most common type of dementia is Alzheimer's disease, which accounts for over half of cases, followed by Vascular Dementia (VD), Frontal Lobe Dementia (FLD) and Dementia with Lewy Bodies (DLB) (Dementia UK, 2011). Brain scan images of people who have dementia show widespread changes usually affecting different regions of the brain (Grabowski and Damasio 2004). This means that the symptoms can vary according to the type of dementia. For example, people with Vascular Dementia are likely to retain function in parts of the brain that control awareness. This can lead to significant high levels of depression. The consequences of brain dysfunction in FLD can lead to aggressive and inappropriate behaviour, even in the mildest-mannered people, and people with DLB are likely to suffer with hallucinations. Although these symptoms tend to be dementia type-specific, in the longer term most people will experience multiple dysfunction that usually lead to difficulties with thinking, orientation, comprehension and calculation, judgment, memory and learning capacity. Problems with language, sleeping, food intake and spatial awareness also commonly feature (Warner, Butler and Wuntakal 2006).

In addition to the physical symptoms, people living with dementia often suffer with psychological and/or psychiatric-type symptoms. To date there is no known cure for dementia. The progressive nature of the condition usually leads to drug intervention at some level to control the symptoms, and eventual admission into long-term residential care.

Even though relevant text books provide standardised descriptions of how people living with dementia might behave, for every individual their experiences are unique (WHO, 2006). In the earlier stages, the changes that people experience frequently engender feelings of fear, helplessness, loneliness and depression. How people deal with these negative feelings is dependent on many factors including past experiences, their personality and their present situation. This applies equally to care-givers who are observing the changes in their loved ones and experiencing the consequences in their own way.

The medical model of illness and dementia

The medical model of illness views ill-health conditions from a scientific perspective, focusing largely on causes, prevalence, progress of symptoms and treatments. Currently there is no definitive understanding of the cause(s) of dementia and no known cure but there are a number of drugs that help to manage the progressive symptoms.

Anti-dementia drugs may help to slow down the progression of symptoms; and anti-psychotic drugs may help to limit problems such as depression, agitation and aggression. However, both types of drugs are limited in their effect. Anti-dementia drugs are helpful for some people, mostly in the early stages. The use of anti-psychotic drugs for people living with dementia has been increasingly questioned over the last decade or so, with many eminent commentators suggesting that their benefits are largely outweighed by harmful side effects (e.g. Sink, Holden and Yaffe, 2005; Banerjee, 2009). In the light of these factors, there is a significant drive to reduce drug prescriptions and to move towards alternative support methods. Not least of these is the therapeutic use of the arts and music and wider societal support (DH, 2009).

Alternative models of illness and dementia

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 dementia (Innes, 2002). An alternative to the medical model is the salutogenic model (see Lindstrom and Eriksson 2010). This focuses on how people comprehend, manage and make meaning of their lives even when faced with significant health disruptions (Sdell, 2007) such as in dementia.

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; Sdell, 2007). From the salutogenic point of view, the condition of dementia 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
- Communication – speaking and expressing needs and emotions
- Living in the world with others – relationships and social life
- Cognition and understanding – making sense of world and making decisions
- Organisation and structure
- Skills
- Physical ability

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, Lipton, Katz et al., 2003; Moos and Bjorn, 2006). In light of these studies, it can be argued that for people who face significant dementia-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 potential co-stressors may be addressed. These observations support the view that, as a creative and social activity, singing regularly in a social environment could support the wellbeing of people living with dementia and the people closest to them by helping them to explore the way in which they deal with life changes.

The following account from a spouse carer who sings with her husband in a dementia-focused group provides an example:

“You have to do the best don't you? You don't know what's round the corner.
You have to get through it so coming – singing and seeing him laughing and enjoying himself – that's like a breath of fresh air.”

The current national policy framework for the care of people with dementia

In England, around two-thirds of the 820,000 people diagnosed with dementia live in the community in their own homes and around one-third live alone (DH, 2009). The Government's most recent recommendations emphasise the importance of delivering appropriate care in the community in order to uphold good quality of life (DH, 2012). The recommendations include a focus on reducing stigma, social exclusion and discrimination, and prevention of premature admission into long-term residential care. Currently, Government funded services that aim to address these priorities are underpinned by the work of family doctors, psychiatrists and specialist staff including nurses, occupational therapists and clinical psychologists in Memory Clinics and Community Mental Health Teams. Local authority social services also provide some means-related funding to address an individual's home and social care needs.

In addition to these formal services a number of voluntary, charitable and third-sector organisations provide support. Examples include the Alzheimer's Society (www.alzheimers.org.uk) which provides a range of training and support for people living with dementia and their care-givers, and similarly, Dementia UK (www.dementiauk.org), which also trains dementia specialist Admiral Nurses. The growing number of Dementia Cafés (Graty, 2008) and carers support groups also offer a choice of activities and support services in a social setting. However, these services are not consistent countywide and they usually rely on the fund-raising efforts of voluntary organisations.

How group singing can help people affected by dementia

Group singing can help support people who are facing a range of challenges arising from living with dementia.

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 dementia.

Communication: Singing can help people with dementia communicate in a number of ways. Firstly, the physical act of singing can reflect the principles of speech therapy for people with dementia. 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 dementia. All of these activities can elicit a sense of expectation, achievement and hope.

Cognition and understanding: Two of the most functional human needs are the capacity to understand and to be understood. Participation in singing social groups is arguably accessible to everybody regardless of their understanding of the world. Accessing tunes, singing, humming familiar songs, swaying or moving rhythmically and a comforting connection with the musical tonic appears 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 on through activities that include group cooperation, such as democratic choices, turn-taking or small-group singing. In addition to new relationships forming, 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 to face the challenges associated with dementia.

Organisation and structure: For people affected by dementia, 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.

Skills: People attending singing groups can contribute in many ways. The collective skills of the facilitator and all participants should be recognised and utilised where appropriate. This may relate to: helping with practicalities; offering suggestions; singing a solo line; leading or contributing to an activity in some way, and supporting others. It has been shown that people living with dementia can learn new musical material. As in all singing groups, it is usual for members to learn at different rates, so those absorb new learning quicker can help to support others.

Physical ability: The physical consequences of singing include muscle mobility in the laryngeal region, face, throat and chest, which can collectively strengthen voice production, improve lung activity and capacity and improve posture. In addition, large and small physical actions, from finger-tapping to dancing can support a whole range of competences from hand dexterity to stability when walking. When shared as a communal activity in singing groups, physical actions can engender a sense of belonging and bonding.

Evidence

Case studies

Case studies can provide the most powerful and concrete evidence of the value of group singing for people affected by dementia. The following represent different models from one-off projects to regular, weekly singing groups that take place across the country.

Over the last decade or so, raised awareness of dementia and the role that singing can play in supporting wellbeing has engendered a number of important initiatives. Some of these deliver one-off or periodic projects that culminate in a performance of some sort. Examples include Turtle Song, a collaborative project with English Touring Opera and Turtle Key Arts, and Our Turandot: Music Through the Telling and MindSONG, both delivered in association with the Alzheimer's Society and Welsh National Opera and Three Choirs [Festival] Plus, respectively. These projects enable people with dementia and their care-givers to write and perform their own song cycles under the guidance of trained musicians/music therapists. They represent one model of engaging people in creative music-making in social environments.

This guide focuses on an alternative model that is designed to be on-going and progressive and may be delivered or co-delivered by a range of people.





Singing for the Brain (groups across the UK)

Singing for the Brain is a service overseen by the Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment.

Groups meet regularly, once a week or fortnight. The sessions are run with the help of volunteers who deal with the practicalities and join in with singing. The sessions last for about one and half to two hours and include a relaxed welcome with refreshments on arrival. After about half an hour the singing leader calls everyone into a circle and uses a greeting song to welcome everyone by name.

Sessions begin with some gentle tried and tested vocal warm-ups and breathing exercises used by singers around the world to strengthen the voice, ease tension and relax the muscles in hands, feet, neck and shoulders. This increases lung capacity and increases blood flow to the brain, helping keep the brain in optimum condition.

Action songs increase the playful exercise element and give challenges to the brain which people with memory problems often cope with very well. Use of rounds, call and response, and other ways of creating simple harmonies helps concentration.

Well known songs are used to evoke verbal and emotional memories. New songs are taught to help challenge and extend skills. Sessions are usually unaccompanied though some leaders occasionally use a keyboard and invite light percussion or other accompaniment from participants. Sessions generally finish with a quieter song as a calming finale, and everyone is thanked and given good wishes until the group meets again.

Everyone is welcome to join a Singing for the Brain group whether they already sing or not, and there is no need to read music. Singing for the Brain groups are led by trained singing leaders who are skilled in teaching songs from scratch at a pace that includes everyone. People from a wide variety of social backgrounds and at different stages of dementia enjoy Singing for the Brain and, after their first visit, they nearly always come back for more.



The Seaview Singers (Herne Bay)

The Seaview Singers singing group for people affected by dementia started in April 2009 in partnership with Age Concern Herne Bay and Music Dot Circus, an organisation that delivers community music activities. The focus was on providing informal carers with an activity that they would enjoy together with the person they care for.

Through a connection with Seaview House sheltered housing, we were very lucky to be offered the free use of a large, airy day lounge. This meant that all of the funding, initially provided by Age Concern, could be used for paying experienced music practitioners to run the sessions and for song books and other material.

All of the practical issues were decided between the carers' support lead, Audra Streeting, and the carers themselves. This included the timing and length of sessions, transport, parking and whether a break and refreshments were needed.

The sessions are now led by a group of experienced community music practitioners, Trish and Nicola Vella-Burrows, Phil Self, Lizzi Stephens and Alex McNeice. Wherever possible, the co-facilitation of sessions is encouraged. Each practitioner brings with them their own skills and personality and those who are not facilitating an activity can help with part singing and experience the session from the inside.

The musical material includes a mix of familiar songs and new songs from a wide range of world music. New songs are chosen for their uncomplicated words/repetitive choruses or lines. Some songs are composed by the practitioners especially for the group. The lyrics might be based on singers' comments or conversations, or on the view from the window, for example, but they are always topical. The singers are also involved in lyric-writing and there is an important improvisational element in which singers compose their own music from scratch using percussion instruments and their voices. This took a little time to establish, as people were less familiar with this type of interaction but it is very rewarding to see the concentration and communication that flows between people that often have trouble with spoken conversations.



Charles Harman, member of Seaview Singers and carer for wife Sheila shares his views of the sessions:

“The sessions were well received by all the participants which included people suffering from Alzheimer’s and their carers; in my case Sheila, my wife, and myself. We enjoyed the sessions which were very lively and great fun, mainly due to Tricia and her colleagues who stimulated us so that we rapidly became a well functioning group. Tricia always started by singing a song as she introduced each person by their first name. That meant we soon knew each others’ names and that has proved useful even outside the sessions. We soon also realised that we did not have to have a good voice, although I was surprised at the standard we achieved in later sessions. A whole variety of techniques were used including using simple percussion instruments and bells in different keys, and coordinated movement and music which even I found difficult. Even the more seriously handicapped were able to join in and you could see from their expressions that they were being stimulated by the activities. I found that after the sessions, Sheila was more lively and seemed more responsive to her surroundings. I thought this was so important that we have joined a ‘silver singing’ group in Herne Bay to continue our singing, and I am taking Sheila to as many musical events as I can; several every week. I look forward to future sessions.”



To date, the group and its activities have grown and developed into a thriving community singing group that has begun to engage with other community and education groups. This includes a partnership with the Department of Music and Performing Arts at Canterbury Christ Church University, for whom the group readily invites and (kindly) critiques supervised students who are learning how to facilitate community singing groups. This has meant that sessions can continue in the face of pending funding problems. It has also provided a highly productive platform for the singers, who give their comments on how the sessions are being run. A new partnership with a local primary school led to an intergenerational 'Song and Tea Party' as part of a dementia awareness programme.

Two of the longest-standing singers were also invited to talk about their experiences on BBC World Service's Health Check programme (Listen to the programme here: www.bbc.co.uk/programmes/p00dy3zc). These developing activities have been important for the group who report really enjoying undertaking and meeting these challenges.

Research evidence on singing and dementia

Over the last two decades, a body of studies have shown that engagement in music, from passive listening to active participation, can alleviate symptoms associated with dementia. Alicia Clair, music therapist and prolific researcher in the field of singing and people living with dementia writes:

“Singing is integral to the life quality of those who are in progressive dementia and their caregivers. It functions to provide islands of arousal, awareness, familiarity, comfort, community and success like nothing else can. It is particularly valuable as an intervention because it is accessible to a wide array of individuals, since it has no pre-requisites for prior musical skills or training, and can include persons across cultures and socioeconomic strata. It is also effective in severe, late stage dementia when responses to other stimuli are non-existent.” (Clair, 2000 p.93)

From a wider population perspective, studies on the effect of singing have shown a relationship between singing in a group and a sense of wellbeing. Clift, Hancox, Morrison et al. (2010) report the largest study on choral singing and wellbeing undertaken to date. Their cross-national survey of 1124 choral singers in Australia, England and Germany showed that singing could support people to cope with significant challenges relating to enduring mental health problems; family/relationship problems; physical health challenges and recent bereavement.

Recently, the Sydney De Haan Research Centre for Arts and Health has established and evaluated a network of singing groups for mental health service users. The project was established in September 2009 in towns across East Kent and it has run for two years. The findings from the evaluation conducted during the first year of this project have provided powerful evidence of the value of singing groups for promoting recovery and maintaining wellbeing among people with a history of enduring mental health challenges (Clift and Morrison, 2011).

Engaging in both listening to music and singing has also been shown to alleviate some of the commonly reported psychosocial symptoms of dementia. These include problems of depression and agitated and aggressive behaviour (e.g. Gerdner 2000; Sung et al., 2006), impaired social interaction (e.g. Cevasso and Grant, 2006) and sleep disturbance (e.g. Lindenmuth et al., 1992) and enhance quality of life (Camic et al., 2011).

The science behind the value of singing has been investigated by studies on hormone levels in the blood and saliva during and after singing activities. Findings show that hormones significant in stimulating memory and social bonding, reducing stress and supporting the immune system are affected by singing (Grape et al., 2003; Kreutz et al., 2004). Studies involving people with dementia also show that the hormone, melatonin (implicated in regulating sleep patterns and Seasonal Affective Disorder), was increased, and stress hormones decreased during and after music activities (Kumar et al., 1999; Suzuki et al., 2004).

The preservation of musicality in people with dementia is commonly observed. The progressive cognitive difficulties normally associated with the condition may be irrelevant because the act of singing appears not to be dependent on an understanding of the world. That people remember how to sing may be explained in part by brain scan images showing that the dorsal medial pre-frontal cortex (associated with autobiographical memories and emotions) is highly stimulated during music activities (Janata et al., 2007). This area is relatively preserved in some dementias and can be one of the last regions of the brain to shrink.

In addition to these studies, a number of others have shown that very young babies appear to connect with music in a way that cannot be explained by musical knowledge/experiences (e.g. Trehub 2003; Tramo 2001). This may indicate the presence of some form of genetic programming to music, which may also account for the commonly-observed connection with music for people even in the latest stages of dementia.

Practice

Guidance on setting up and running singing groups for people affected by dementia

The facilitator

The role of the facilitator is of key importance in any musical group. The facilitator of a singing group for people living with the effects of dementia ideally needs to be:

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

Prospective facilitators may not always possess all of these ideal skills. Some may feel in need of training in one or more areas. A good way forward would be to contact organisations/projects/individuals with experience in their less familiar areas to explore possibilities for mentoring or training. Some ideas 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 affects of dementia, 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 musically relevant to include a Nepalese lullaby, for example, because it presents musical elements that can help the group to develop certain techniques, or an African call-and-response chant for its 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 more so in groups of people affected by dementia 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 singers may have previously 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 Seaview Singers' repertoire is very wide and varied. Many short call-and-response songs and ditties are especially composed for the group by the facilitators. They are designed to protect and develop the voice and breathing apparatus over time and are based on established singing techniques. In terms of more conventional songs, these are initially suggested by the facilitators, who judge their suitability in terms of subject and musical and development potential. There follows some dialogue with the singers to ascertain each song's relevance to the group. This process allows for collective ownership of each song, which is then used as a basis for developing repertoire.

For example, the folk song 'Oh No John!' was chosen for singer, John, who was invited to sing the chorus with a small group of others, then with just two singers and finally, with unexpected vigour, as a solo. The folk song, 'Skye Boat Song', was sung by all of the singers in their young lives and by each of facilitators at school. One singer had spent time in the Hebrides as a child and recounted stories of her time there whilst others listened respectfully. During the lilting, lullaby-like chorus, singers began to sway in the same direction. Most remembered the words to the chorus, so the words to the first verse only were repeated in the verse section and the chorus was always repeated at the end of the song several times. Over time, a small group of care-givers volunteered to learn a descant to the chorus and later, to the verse. The song has become one of many that feels special to the group and was part of a specially performed programme for personnel from Age Concern, Herne Bay and the Community Mental Health Team.



In addition to a wide range of folk songs, the repertoire includes sea shanties (e.g. What Shall We Do with the Drunken Sailor; Bobby Shafto); gospel songs and spirituals (e.g. Swing Low; This Train is Bound for Glory); hymns (e.g. All Things Bright and Beautiful; Amazing Grace); songs from shows; (e.g. Memory; Supercalifragilistic); pop songs (e.g. Lollipop; Rock Around the Clock); multi-cultural songs (e.g. Bella Mumma; Hey Dumba). These latter songs have simple repeated words and tunes. Where appropriate, they, and other songs, are sung in two or more parts, with the second and third parts sung by small groups of two or three singers and the facilitators. There is often a great sense of pride and achievement when a new song, or a second/third part is achieved. The maxim is always set up attainable goals. Once one goal is fulfilled, another is set.

Not least of a challenge is the group's engagement with song-writing/composition. At the present time they have re-written some of the lyrics to the song the 'Quartermaster's Store'. In this, they replace every item in the store, for example 'bread', with the name of a singer, for example, 'Charles', and follow on with a rhyming action. So, the two lines, 'There were mice, mice eating all the rice...' and 'There was bread, bread as hard as lumps of lead...', were replaced with, 'There was Ann, Ann, looking for a man...', and 'There was Charles, Charles, full of happy smiles...'. In addition to having a lot of fun experimenting with lyrics, the singers are invited to improvise rhythmically on percussion instruments. The music grows organically with one player starting and others joining in and resting at will. As well as being a powerfully communicative activity, the process is designed to help people feel uninhibited about experimenting musically. It is hoped that it will lead to the singers feeling confident enough to compose the words and music for an entire song.

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 dementia, 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 dementia, 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 dementia, a number of pre-validated questionnaires are used. These include questionnaires to describe the severity of dementia, such as the Clinical Dementia Rating Scale (CDR); questionnaires to describe changes in quality of life, such as DEMQOL and DEMQOL-Proxy (Smith et al., 2005; 2007); questionnaires to assess cognition, such as the Mini Mental Status Examination (Folstein et al., 1975); and to assess behavioural and psychological symptoms of dementia, such as the Neuropsychiatric Inventory (NPI) (Cummings et al., 1985).

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 dementia 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 dementia-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.

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)

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

Major dementia charities

The Alzheimer's Society: The Alzheimer's Society one of the UK's leading support charities for people affected by dementia. In addition to connecting its 25,000 members to each other through an online forum, the charity provides information on a wide range of topics and signposts people to service and support agencies. They also push forward the research agenda and work to raise awareness across communities. www.alz.org.uk

Dementia UK: Formally, 'for dementia', Dementia UK committed to improving quality of life for all people affected by dementia. The charity train Admiral Nurses, specialist dementia care nurses who provide practical and emotional support in people's homes, and provide a wide range of training course for people with dementia and those caring for them. The charity also hosts a national network for unpaid care-givers, who are involved with training professionals, speaking to media, contributing to research and fundraising. www.dementiauk.org

Singing and people with dementia

Singing for the Brain: A service overseen by the Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment. www.alzheimersuk.org

Sing For Your Life: A registered charity established in 2005 to improve quality of life, health and wellbeing for older people through participation in musical activities. The core activity of Sing For Your Life is a network of Silver Song Clubs, regular sessions of social and community music making for older people. There are now over 30 Silver Song Clubs meeting across the South East of England. Sing For Your Life also support some Singing for the Brain groups. www.singforyourlife.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

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

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

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

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Sing for your life



“These will be invaluable texts for anyone interested in music, health and wellbeing. Not only are they concise, clear and accessible but they provide exemplary examples of much needed research exploring the benefits of musical participation.”

Professor Raymond MacDonald,
University of Edinburgh

“The Sidney de Haan Centre is to be congratulated for their work in first obtaining strong evidence for the benefits of singing and then creating these pamphlets so as to translate findings into community practice. The well organized presentation serves as a model for other countries and deserves recognition for showing the way to more initiatives both within and beyond the UK.”

Professor Annabel J. Cohen, Director, AIRS
(Advancing Interdisciplinary Research in Singing)
University of Prince Edward Island, Canada

“Clear, concise and thoughtful guides that will help community musicians understand health issues and healthcare systems; and health professionals understand the role of good-quality singing work in a range of conditions.”

Kathryn Deane,
Director, Sound Sense

“I cannot praise these Guide packs highly enough. I have been running training courses for those wishing to run groups and choirs since 1988. Increasingly people coming for training wish to work in the area of singing for health and well being, many of them bringing relevant backgrounds in the health and caring professions. The practical suggestions lay out all the essential aspects of running non-judgmental and inclusive groups.”

Frankie Armstrong, Founder,
The Natural Voice Practitioners' Network

