

## **CASE FOR SUPPORT**

### **Pathways Singing Program**

*Helping people with dementia find their voice through song*

#### ***Dementia: the global epidemic of the 21<sup>st</sup> century***

Dementia refers to a progressive and generally irreversible condition where mental functions are disrupted. Dementia is characterized by memory impairment and reduced ability in at least one other global cognitive function (i.e. comprehension, learning, language) with an associated change in personality (i.e. lack of motivation, loosening of emotional control, coarsening of social behavior) as well as a decline in overall functioning (Pace, 2011). The average interval from diagnosis to death in dementia is eight years, though many people live up to 20 years.

Older age is the single most important factor for the onset of dementia. The prevalence of dementia doubles every five years after the age of 65. Other factors may include Down's syndrome (high risk over age of 40), genetics (having two copies of the apolipoprotein E4 gene), poor education (people with higher levels of education function better with the same level of pathological change), vascular factors and heart disease (i.e. hypertension, obesity, high blood cholesterol levels, diabetes) (Pace, 2011).

Dementia presents itself in three stages: early (need for supervision), middle (need for care) and advanced (need for nursing care). In early dementia, difficulties occur with managing daily life i.e. planning, organising, carrying out complex tasks or usual activities. The person's mood and social behavior may change, becoming distant and withdrawn. The person will retain awareness of their situation and be able to contribute to discussions and decision about living and care (Pulsford & Thompson, 2013).

The middle or moderate stage includes more profound memory problems. The person may have lost awareness of her condition and will likely have problems understanding complex concepts. More impairment in orientation of surroundings and time as well as language such as sentence construction occurs. Changes in behavior or personality may occur. Activities of daily living become more difficult.

The advanced stage of dementia will probably involve receptive aphasia (not understanding words spoken). Verbal communication may consist of repeated words, phrases or utterances that are hard to understand or may become completely non-verbal. Disorientation may now include the inability to recognize people. Field of attention becomes reduced and only simple activities can be carried out.

Incontinence, and physical frailty as well as becoming dependent on others for help with activities of daily living (eating, dressing, bathing) mark this stage.

The average duration of dementia is eight years, though many people live up to 20 years. The average lifetime cost per patient in care is \$174,000 with an average of \$12,500 per year being paid by the family. It has been called the “disease of the (21<sup>st</sup>) century” (Brummel-Smith, 2008).

The World Health Organization recognizes that dementia will reach epidemic proportions globally in this century. One in 11 Canadians over the age of 65 has some form of dementia and numbers are increasing exponentially (*Canadian Alzheimer’s Society*). Approximately 80% of residents in long term care or nursing homes live with dementia (*Ministry of Health and Long Term Care*). Additionally, many people living with dementia are cared for by family members at home.

### ***Music for whole person care***

Music reaches deeply into all aspects of human life. It helps distract us from pain or get a better sleep. It helps us manage feelings or shifts in our mood. Music can bring order for a confused mind and provide memory stimulation. It gives us inner peace and comfort. Because music reaches us on many levels, touching the whole person, it becomes an effective means of care.

### ***Why music works in dementia care***

Music is considered by many experts as a natural choice in helping people living with dementia. An excellent demonstration of this is how personalized music enhances the life of Henry, an older man living with dementia, seen here: <http://www.youtube.com/watch?v=fyZQf0p73QM>

Health care providers and family caregivers know that there is something unique about people with dementia’s response to music. There may be severe cognitive loss and limited communication abilities, but the person with dementia may be able to identify a familiar tune. There are a number of studies that verify these experiences.

Evidence suggests that music supports people living with dementia in a number of ways:

#### **1. Improved memory and recognition**

- Recall - Words of long-familiar songs were remembered better than words of stories or of prose (Prickett & Moore, 1991; Samson et al, 2009)
- Facilitating function – memory of tunes and lyrics may be resistant to neurological disorders due to temporal processes (Vanstone et al, 2009)
- Improved verbal and non-verbal memory (Sambandham & Schirm, 1995)
- Maintained procedural memory (Beatty et al, 1999)
- Recognized familiar music and musical emotions (Cuddy & Duffin, 2005, Drapeau et al, 2009, Samson et al, 2009, Vanstone & Cuddy, 2010)
- Correctly perceived pitch and melody of music (Johnson et al, 2011)
- Recognized title of familiar songs (Johnson et al, 2011)

## **2. Improved quality of life**

- Improved speech fluency (Brotons & Koger, 2000)
- Improved autobiographical recall (Foster & Valentine, 2001)
- Increased mood and engagement through reminiscence therapy which may include music (Woods et al, 2008)
- Improved motor skills, gait and engagement through rhythmic music (Mathews et al, 2001, Clair & O’Konski, 2006)
- Reconnection with beauty and the spiritual life (Clair, 2000)

## **3. Reduced behaviors and symptoms**

- Alleviated apathy (Holmes, 2008)
- Reduced agitation (Gerdner, 2000, Ziv et al, 2007, Ledger & Baker, 2007, Ballard et al, 2009, Suzuki et al, 2004), especially at mealtime (Hicks-Moore, 2005)
- Reduced activity disturbance (Raglio et al, 2008).

### ***Singing and dementia care***

Singing, as a mean of music-making, is particularly beneficial in dementia care because it is a healthy and meaningful activity. Singing encourages deep breathing, increases blood oxygenation and induces muscle tension release which provides relaxation. Singing provides a point of human contact. Singing is a meaningful activity that may provide emotional connection and intimacy, connecting people living with dementia to prior experiences where they were held, rocked, patted and sung to when they were in need of comfort. An excellent example of this is Gladys’ story:

<http://www.youtube.com/watch?v=CrZXz10FcVM>

Singing retains its value through all stages of the dementia trajectory. In early stages, singing is a viable and recognizable intervention as cognitive capacities are becoming lost. In mid-stage, singing provides a way for persons to have experiences that are normal, focused and purposeful. In late stage, caregiver singing provides stimulation that elicits responses such as moving the head to locate sound, eye blinking, eye movement. At end of life, singing offers a way for everyone present to engage with each other, providing a context for transition.

Singing is an opportunity to actively engage in a form of communication where language has been affected by illness or trauma. The ability to sing is neurologically different from speech and is more instinctive than speech. Singing may also provide neurological pathways for memory retrieval as research suggests music pathways may still be intact in dementia.

### ***Pathways Singing Program: helping people with dementia find their voice through song***

Pathways is a singing program whose purpose is to enhance the quality of life for people living with dementia and their caregivers. Pathways will create an opportunity for people living with dementia and their caregivers to connect with themselves and others in a number of settings, including long term care, community and day programming and in home settings. It can be used in large groups, small groups and

with individuals. Users of Pathways will include LTC program leaders, dementia daycare program leaders, recreation therapists, Alzheimer’s Society group leaders and caregivers.

The three main objectives of the program are to:

- ❖ provide the opportunity for *people with mild to moderate dementia* to have meaningful social interaction and improvements in quality of life through a singing program
- ❖ allow *caregivers* the opportunity to participate in a social activity with their loved one, providing much needed respite from their caregiving and enhancing caregiver wellbeing
- ❖ provide *community and/or program leaders* with a music program based on research and best practices that can complement their existing social and recreation programs

The Pathways Singing Program is comprised of 3 components:

- 1) **Video series** – Twelve 30 minute episodes. Each episode will contain a welcome, breathing and warm-up exercises, five songs sung 2-3 times each, moving from slower to faster in pace. Words or vowels or syllables may be used when singing while words and cuing pictures are on the screen. Each episode concludes with a final breathing exercise and a goodbye. DVDs will be simple, consistent and calming in their approach, featuring the same singing host in each episode for familiarity, regularity, repetition and focus.
- 2) **Activities** – Each episode will have five accompanying activities per song. This is meant to extend the usefulness of the musical experience, integrating other modalities and enhancing the program. Trivia and background material for song selections will be included in each episode. This represents five hours of benefit-designed activities per episode for a total of more than 60 hours of activities that can be repeated over and over again.
- 3) **Training Modules** – Pathways is meant to be delivered by caregivers: program leaders, care providers, volunteers, and family caregivers. Those delivering the program do not have to be music experts. An online training resource will train and support program facilitation in whatever setting Pathways is used.

The outcomes for participants in the program are:

- ❖ engaging in safe social interaction
- ❖ triggering memories, language, emotions
- ❖ catalyzing new experiences
- ❖ providing alternatives for caregivers

A team of experts, including consultants representing long term care, recreation therapists, the Alzheimer’s Society, music therapists, dementia researchers, caregivers and others, will design the program using best practices.

A Pilot Study was conducted in 2011 (Room 217 Foundation and the University of Windsor Music Therapy Department) in more than 20 LTC facilities across Canada with positive results. Study results confirmed that:

- Trivia questions stimulated discussion and reminiscence.
- Overall pacing and timing of the program was appropriate and effective for clients with cognitive impairment, but not for clients who were cognitively intact.
- Duration of the video (30 minutes) was seen as effective and appropriate.
- Tempo of the music was just right.
- Breathing exercises were beneficial and described as a great activity to improve health.
- Songs were recognizable, and the vocal range was appropriate for the residents. The lyrics were easy to sing along with and the vowels and syllables facilitated singing and stimulated movement.
- Program increased social engagement with residents, distraction from worry and pain, improved cognitive awareness, reminiscence, emotional health and quality of life.

Three focus groups of more than 30 dementia care experts, family caregivers, community stakeholders and people living with dementia were conducted in Durham Region, Toronto and Waterloo, Ontario in 2013. Presentation of content from the Pilot as well as implementation strategy was discussed. Feedback from these groups was overwhelmingly positive and provided helpful advice for program development and implementation. Comments included:

- *“This is the program we have been searching for.”*
- *“This will fulfill an unmet need for a good, high level music resource for dementia.”*
- *“All the work is done for us which is the support we really need.”*
- *“It has visuals and sound, it is uplifting, hopeful and engages all of the senses (different from current resources).”*
- *“Caregivers are exhausted, this will be a nice break for them and caregivers enjoy music too. It will allow them to share an enjoyable activity with their loved one.”*

The Pathways Singing Program will be initially launched in 15-20 centres in the GTA as well as 2-3 Alzheimer’s Societies and day programs for dementia. The program will then be rolled out across Canada through our existing national database and through various societies and LTC head offices e.g. the Alzheimer’s Society and Chartwell.

### ***The Room 217 Foundation***

The Room 217 Foundation is a not-for-profit corporation and registered Canadian charity that creates therapeutic music resources which reach across the lifespan to provide comfort and support in a broad range of circumstances. Room 217 is unique because it provides leadership in resource development, education in music care and it builds bridges amongst music care providers. Music medicine research is used to inform the development of the music which is what sets Room 217 apart from other music organizations or charities. For example, slowing the cadence of the music to 60 beats per minute (bpm)

can help to lower heart rate and create a sense of relaxation and calm. The Room 217 CD Music Care Collection and Recollection DVDs were professionally produced using familiar music recorded live in a studio at 60 bpm and are currently used by caregivers in hospices and palliative care units throughout Canada.

In addition to producing and delivering therapeutic music care resources, The Room 217 Foundation provides skills and training for integrating music into care through workshops, the annual Music Care Conference, and starting in 2014, the Music Care Certificate program. Future goals of the Foundation include support for music care research to inform practice. Please see [www.room217.ca](http://www.room217.ca) for a complete outline of what the Foundation does, the music resources it has produced and personal stories based on the use of these resources.

### ***Program Relevancy***

Room 217 is uniquely positioned and experienced to develop the Pathways Singing Program. In “caring for the whole person with music”, the Room 217 Foundation excels in putting well researched music resources into the hands of those who need it most.

The Pathways Singing Program will fill an unmet need for a much needed music resource for caregivers and community leaders working with people with dementia. It will also provide an enjoyable psychosocial activity for people with dementia that has the power to unlock both their memories and their voice. The importance of this activity is captured in a quote from a caregiver who currently uses the Room 217 music care collection with people with dementia.

*The special man for whom I bought the Room 217 Country Road CD was having a particularly restless morning. He is young---just turned 61--and has been with us for three years already. No nursing home will take him. He has a very advanced frontal lobe dementia which, at present, leaves him with little speech except for the occasional "no!!" or a simple yell. He paces constantly. From morning to night, if he isn't pacing, he is sitting only momentarily at the edge of his bed. I brought the CD player to his doorway, turned it on and was quite frankly stunned to see his reaction. He stopped pacing, stood perfectly still, started to simply walk himself around in a small circle (something brand new) and when he did start to pace again, it was much more slowly, much more calmly and every once in a while, he would turn again in a circle. I had brought in a glider rocker to his room before the music began and after four songs, was able to guide him to sit. And he did, for three more songs! And tap his toes to the beat. Incredible! He had not sat still for more than 4-5 seconds in months. It brought me to tears.* - Theresa P. nurse

### ***The Pathways Singing Program Fundraising Campaign***

The Pathways Fundraising Campaign is seeking to raise \$300,000 for the Pathway Singing Program over the next two years in order to support the design, production and delivery of Pathways. The efforts of

The Room 217 Foundation are primarily supported by donations. Donor investment will support the following activities (design and production will take place in the GTA area):

- Design therapeutically effective programming for caregivers and allied health care professionals
- Produce Pathway resources and activity materials
- Identify Pathways program participants
- Develop and implement online training
- Support Pathways facilitators
- Roll Pathways out provincially and nationally
- Provide meaningful activities for people living with dementia and their caregivers

### ***Program Financials***

	<b>Amount</b>	<b>Comments</b>
Campaign Goal	\$300,000	Over 2 years 2014-2015
Funds raised to date	50,000	Prior to 2014
Key Cost to produce and distribute Pathways	\$272,000	Includes project management, program/training/online creative development, audio/video production, manufacturing, implementation and delivery
Fundraising cost	10,000	
Administration cost	18,000	
<b>TOTAL</b>	<b>\$ 300,000</b>	

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