FOREWORD BY RICHARD GILL, AO

# MUSIC REMEMBERS ME



CONNECTION AND WELLBEING IN DEMENTIA

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Published by HammondCare Media 2017
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10 9 8 7 6 5 4 3 2 1



Editoral team: Catherine Proctor, Peter Hallett and Christina Maurice
Cover and internal design: Melissa Summers of SD Creative
Printed in Australia by SOS print + media on FSC stock

National Library of Australia Cataloguing-in-Publication entry
Creator: Beilharz, Kirsty, 1971- author.
Title: *Music remembers me : connection and wellbeing in dementia* /
Kirsty Beilharz.

ISBN: 9780994546111 (paperback)
Notes: Includes bibliographical references and index.
Subjects: Dementia--Patients--Rehabilitation.
Music therapy.
Music therapy for older people.
Dewey Number: 615.85154

Cover photo: Much-loved Marion Vassallo (1926–2016) singing along happily to *Dear Old Dolly* at HammondCare Woy Woy. Photo by Sophie Timothy. Thanks to Marion's family for permission to use this photo and for their support of *Music remembers me*.

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# FOREWORD

Plato said: *'Music is a moral law. It gives soul to the universe, wings to the mind, flight to the imagination, and charm and gaiety to life and to everything.'*

Those hoping to make the case for music stronger, and further hoping to increase their advocacy, often resort to these words from Plato with very good reason.

However, Plato would be thrilled to know that music is a potent force in healing and that the work now being done with music—for people living with all manner of disorders, including cognitive—is having a profound and extraordinarily telling effect on their conditions.

The evidence for the efficacy of the use of music for people living with dementia, for example, is now well documented. Neuroscientists and medical practitioners working with people with cognitive disorders are spending a great deal of research time building large banks of very convincing evidence, which is now available worldwide.

These developments are to be celebrated at every level, which is why it such a pleasure to be able to write a few words in support of a new book which examines these issues.

*Music remembers me: Connection and wellbeing in dementia* is for the general reader. While the research is available for professional medical practitioners and allied workers, very little is available in the way of useful information for the everyday person who may be affected by dementia in some way.

Kirsty Beilharz has taken the bit between her teeth and produced a book which will inform the general public of this important work, in language and narrative which can be read with ease. More strength to her arm!

I wish those involved in these endeavours continued success and congratulate Dr Beilharz on her enterprising and important initiative.

**Richard Gill AO**

# PART 1
# How music helps people with dementia

*'Music remembers me* arises from HammondCare's approach of translating research into action in everyday care, with the aim of enabling a more sustained music practice.'

# CHAPTER 1
## Understanding the basics

Research has found many benefits of music for people with cognitive impairment, dementia and the carer relationship, but these results have previously only been published in scholarly or expert medical literature. These are journals normally read by gerontologists, psychologists, psycho-geriatricians, physicians and music therapists.

The purpose of this book is to bring those research findings into practice, to help the wider community, people living with dementia and those involved directly in care—family members, home carers, professional care staff, friends, managers and practitioners of music and life engagement services.

Until now, most musical interventions in dementia care conducted for the purpose of research enquiry and testing innovations have been:

short-term interventions

administered by experts

subsequently withdrawn

in clinical settings.

*Music remembers me* arises from HammondCare's approach of translating research into action in everyday care, with the aim of enabling a more sustained music practice for people at home in their community, in residential aged and dementia care and with further extension into palliative care.

Best practice dementia care aims to promote dignity, self-esteem and autonomy, whether that comes from individual-centred, personalised care and choice in residential care, or assisting older people living with dementia to remain at home, and supporting carers. For HammondCare, the use of music is an integral part of our whole-person approach to ageing well, which promotes:

- listening and relating
- enabling choice
- tailoring care individually
- partnering with family and friends
- nurturing the whole person
- being creative and innovative.

## Understanding dementia

There are many books and online resources that describe in detail the effects of dementia, so this section provides just a brief context in order that the interaction between music and the person with dementia can be approached usefully and realistically.

*If you have a good understanding of dementia you may like to skip ahead to the heading, 'Music: why understanding dementia is helpful'.*

Dementia is not a specific disease but rather it describes a range of symptoms. Among these, impairment of two or more of the following is typical:

- memory
- communication and language
- the ability to focus and pay attention
- reasoning and judgment
- visual perception.

This bears out in difficulty such as short-term memory, losing things, problems planning activities, remembering appointments and travelling in unfamiliar surroundings.

People may notice:

- memory loss that disrupts normal life
- challenges solving problems
- difficulty with familiar tasks at work or home
- withdrawal from social activities and favourite hobbies
- changes in mood or personality such as uncustomary confusion, suspicion, depression

- feelings of fear or anxiety
- decreased discernment with finances or personal hygiene.

While every person with dementia has a unique journey, it is usually a progressive condition. This is one area in which music can be particularly helpful, because its efficacy endures throughout the advance of dementia and outlasts verbal communication. As we will see, well-timed music listening can be helpful in supporting a range of needs.

Dementia is caused by damage to brain cells that prevents them from normal communication, which, in turn, affects the thinking, behaviour and feelings associated with the specific region of the brain.

Synapses are cells joined together in a neuron 'forest' and electrical signals travelling through synapses form the basis of memories, thoughts and feelings. These are the chief type of cells affected by Alzheimer's disease,[2] which disrupts this mechanism of electrical charges and the activity of the neurotransmitters. Alzheimer's disease eventually destroys nerve tissue in the brain, and shrinks the hippocampus while the fluid-filled ventricle spaces grow larger, leading to overall diminution of brain mass and capacity in thinking, planning and remembering.

There is a wide variance in the range of time of diagnosis and the progress of disease. It is thought that tangles in the neural pathways and plaque deposits impair delivery of nutrients and the quality of blood and oxygen supply, while also disrupting natural synapse communication between cells. These tangles affect speaking and understanding speech, and what clinicians call proprioception—the spatial sense of the body in relation to surrounding objects.

This manifests as impaired comprehension, expression and difficulty with spatial orientation, distance judgement and depth-of-field discernment.

For example, a person with dementia may have difficulty understanding instructions, moving around their home or garden, eating, or finding bathroom fixtures. Colour contrast between floors and walls, crockery and tablecloths and bathroom taps and basins, as well as effective indoor lighting and other visual cues can assist in spatial orientation. Similarly, there are modifications in environmental design that can help the auditory experience for the person with dementia (these are discussed in Chapter 9 'Creating a good listening environment').[3]

# CHAPTER 2
## Benefits and potential of music

*Grace is a former banker who has advanced dementia. She has little comprehensible dialogue, however she can be lively and enthusiastic and music can variously stimulate, engage or calm her. It is very clear Grace experiences great joy whenever listening to her iPod with staff. Her husband is very appreciative that music has been found to encourage calm feelings and also to enthuse her. The expression on Grace's face while listening to music is undoubtedly one of pleasure.*

Embedding musical engagement in a rounded program of dementia care (residential or in the community) provides a doorway for connection and wellbeing, especially for people who may be emotionally isolated, depressed, sedentary, or unable to communicate verbally.

Music has the potential to:

- provide awakening, stimulating and emotional experiences, after procedural and semantic memory have declined
- tap deep memories of significant life events
- move people emotionally without depending on memory
- affect the taste of food and stimulate appetite
- promote movement or balance and confidence through participatory activities
- act as a conduit for carers and family members to share experiences and build their relationship with the person with dementia
- serve an important role in the journey for both the person with dementia, carers and family by creating lasting shared experiences
- help with mood elevation and revitalisation

- assist with changed behaviours by reducing anxiety, pain and depression
- lead to a reduction in pharmacological prescription of antipsychotic and antidepressant medications[11]
- assist with eating, personal grooming, bathing and other routines
- be used as part of rhythmic entrainment to assist independent walking and fluidity of movement in Parkinson's disease and Huntington's disease.[12]

When certain specific tasks become more difficult with dementia—speech, memory of daily tasks, spatial perception—pragmatic strategies using music engagement can help the carer at home or in the community meet people's needs for companionship, belonging, security and safety. These include (explained in Part 2) individualised listening playlists, participatory group activities, as well as interactive tailor-made musical instruments and interfaces designed for non-specialist use by older people with their everyday carers.

## Emotional connection and visceral responses

Dementia affects communication and expression in ways that can baffle family members, defeat verbal communication, cause distress to the person with dementia and lead to isolation from loved ones, friends, and community.

Music is a non-verbal communication channel that is capable of affecting emotions while being non-literal, non-representative and abstract. It affects us at different levels—cognitive, visceral or palpable, and emotional, and it can be experienced through vibration and movement. For these reasons, music seems to outlast isolated functions affected by dementia, such as speech and memory and does not depend on rational understanding or concrete interpretation to convey emotional experience.

In fact, emotional connection is not contingent on speech, structural comprehension of the music or procedural and semantic memory. This is why people can often still enjoy music, and even sing words, when they no longer have speech and why music can still have an emotional impact when reminiscence and association are no longer present.

The left hemisphere of our brain controls language and reasoning while creativity is primarily identified with the right. Music has both logical and linguistic characteristics (left side of brain), and obviously has creative elements (right side) and yet it does not need full functionality in both brain hemispheres in order to impact our emotions. Nor is musical communication lost in frontotemporal lobe dementia. In advanced dementia, music can provide a means to connect when other methods of communication, emotional expression and recognition deteriorate.

## Communication, shared experiences and awakening

The memory of people with dementia gradually erodes, starting with episodic memory (the 'subjective experience of explicitly remembering past incidents') and semantic memory, (concepts and facts not related to personal experience, e.g. names, places, mathematical equations). These memory changes manifest in lack of concentration, forgetfulness, anxiety, making mistakes in familiar tasks and forgetting people and events.

Procedural memory relates to remembering how to do things, enabling us to develop skills and habits to engage in tasks and procedures. This kind of memory can be retained even if the brain is damaged, e.g. musicians can often recall how to play music after brain damage and destruction of semantic memory. But while aspects of procedural memory can function without memory of our history, it is difficult to find meaning and understanding of who we are in the present if we cannot process the past.

### *From reminiscence to emotional support*

Dementia, in all its forms, eventually leads to profound loss of episodic memory and identity. In this sense, the capacity of music also changes over time. Music moves away from being an aid to reminiscence—triggering memory and story retelling—and gradually becomes an emotionally and physically rousing stimulus not contingent on memory or meaning to be appreciated and enjoyed.

The wonderfully exciting aspect of using music to engage with people with dementia lies in its ability to reach people emotionally and create positive experiences, even when dementia has advanced. We believe that the basic traits of humanness or personhood, such as a sense of belonging, purpose, feeling included and not lonely, are

# CHAPTER 8
## How to tailor the listening experience

*Tatyana is a poised and dignified lady of Eastern European background. While she does not speak, she often looks around and seems interested in what is going on, yet due to her language background she can be isolated. Even among staff from diverse international backgrounds, nobody in Tatyana's residential care home is able to speak her language and her English is quite minimal (possibly dwindling with dementia). On one occasion, I [Kirsty] brought a colleague to meet Tatyana who speaks the same language and has a good command of cultural subtleties of different regional groups. While conversation was still somewhat disjointed and unclear, my colleague was able to 'glimpse' fragments of sentences and responses to music that helped us develop a better picture of Tatyana's musical tastes. We established that she probably had learned piano and preferred classical music. We auditioned numerous examples of classical piano repertoire such as Chopin, Tchaikovsky, Liszt, Mozart, and we explored some other orchestral and operatic masterpieces until we found pieces that Tatyana recognised and appeared to enjoy. One insight my colleague gleaned from their stilted exchange was that Tatyana liked the headphones and immersion in music because it blocked out the noise from residents' TV, radio or talking and calling out. A few months later, I watched her nodding in time to the songs when a choir visited: clearly engaged in the music, although the American Broadway musical tunes and words were probably unfamiliar. Tatyana was not singing but she was keeping the beat and participating in the group event. Music is one of the few ways that staff can connect with and relate to Tatyana that is not contingent on a shared mother-tongue.*

In personalised engagement, music is:

- the 'vehicle' to facilitate conversation, reminiscence, emotional connections and responses
- a motivation to do something together and enjoy emotional experiences
- a tool in narrating and retelling someone's story and preserving and emphasising personhood, individuality and character, rather than medicalising their condition and symptoms
- an alternative to speech for communication
- a method of connecting for young family members and visitors.

This chapter is a practical set of 'how to' guidelines for the carer at home or care worker in community or residential care, who wants to prepare music on a device and help tailor the listening experience to the person with dementia. The guidelines may also provide ideas for the person living with dementia in their discussions with family, friends and carers.

There are music examples in 'Appendix 1 Music by style and culture' to help seed playlists, or to start conversations about what music is liked.

The following suggestions are based on the practical experience of the Music Engagement Program of HammondCare and the Dementia Centre, working with people both at home in the community and in residential care.

## Thinking about the person first

Before we move to the technology that might be used, let's think about the person and the caring relationship and how music can provide support.

### *Rhythms and routines*

Get to know the person in care's circadian rhythms (natural body-clock) and routines. Be aware of times of tension, concern, sleepiness and agitation.[83] It is good to introduce music when the listener is receptive, rather than after stress or discomfort has set in, hoping to retrieve the situation. Especially when you are first beginning to use music in this way, it is important to establish a favourable experience with listening to music.

### *Before distress*

As we have mentioned, agitation is a common experience in some stages of dementia and may be an expression of anxiety or another area of need. Preventing agitation has been found to be more successful than using music as a retrospective intervention. If music is being introduced to assist someone bathing, to alleviate distress, agitation or anxiety, to distract someone from walking, calling out or aggressive behaviour, once again it is preferable to anticipate the trigger.

### *Be proactive*

Psychological triggers often form a pattern and the carer, who knows a person well, usually recognises the kinds of situations that lead to feelings of discomfort or distress. In other words, we are advocating using music proactively to calm a person and provide enjoyable emotional experiences, rather than to view music as a 'curative' or 'antidote' retroactive intervention.

## Choosing the right approach

With these thoughts in mind, let's consider the practicalities of introducing personally-tailored music, including suggested approaches to technology.

### *Choosing a music-player*

We recommend Apple iPod™ Shuffles (at the time of writing) due to the simplicity of the controls, charging and maintenance of the device, the appealing bright range of colours, and the robust construction of the device. The music-player does not require understanding of touch-screen gestures and, because it has no screen, it does not require fine dexterity and sharp eyesight to utilise the device like the more elaborate music-players do.

It does require that music is put on from a computer with an iTunes Library, however the software provides access to one of the largest commercial music sources. Alternatives include different brands of MP3 music player, loading on music from CDs, or devices supported on the Android platform and various other music stores.

The criteria for choosing the technology platform are determined by what is best for the person with dementia, and for the carer or staff. The guiding principles are: