



HIDDEN VOICE

GIVING A VOICE TO DEMENTIA

Hidden Voice is the unique multimedia piece to raise awareness and give a voice to people living with dementia through the beautiful melodies of their speech. Music and speech become one so that the melodies in the speech create the music and the music in turn unpacks the emotional content embedded within, turning the lyrics of everyday life into a powerful and poetic message. Featuring the real life testimonies of people living with dementia, family members and carers, Hidden Voice aims to make you think, to raise questions and deepen our understanding about one of the most important issues of our time.

‘It made me think about the internal emotional lives of people living with dementia, the emotional lives of their carers, and the potential for music to be a positive tool for comfort, support, stimulation and communication.’

*Dr. Katie Overy - Senior Lecturer in Music Psychology,
Edinburgh University*

“A unique relationship between music and dementia”

*Professor Alistair Burns
– NHS Clinical Director
for Dementia*

“It made me feel understood”

Becky, Carer –
Hebden Bridge



SOME YOU REMEMBER

Understanding the signs, early and moderate dementia, living well with dementia.

A lady, approaching her 90th birthday is talking about her life and is asked by a support worker where she came from: "Oh, no I can't remember – my memory isn't as good as it was". She is aware of herself and her condition and seems relaxed and in control: "There's so many things" she says "so many things – some you remember and some you don't".

The care worker asks her if there's an important date coming up. She pauses for a second and says: "Oh yes – it's my birthday – it's tomorrow – isn't it?". "11th February my birthday – I'll be 90". She laughs gently: "I never thought I'd live to be 90. Yet when my children were younger my eldest son said: "mum, you'll live to be 90" and I said: "Oh I hope not". She laughs again.

This lady is living well, displaying a command of important memories and sharing a sense of humour.

TO THINK ABOUT:

What are the signs of early onset dementia?

How should you respond to someone with early onset dementia?

"There's so many things. Some you remember, some you don't."

MYTH:

Dementia is one illness

REALITY:

Dementia is a word for an umbrella of conditions including:

Alzheimer's Disease
Vascular Dementia

Dementia with
Lewy bodies

Frontotemporal
Dementia

Mild Cognitive Impairment
Posterior Cortical Atrophy
Primary
Progressive Aphasia

THERE'S STILL SOMETHING IN THERE

Communication

Tony visits his mum who has dementia with an assessment of 'moderate' but without capacity. They share a close and loving relationship with a lifelong passion for following Wigan Rugby Club. He reflects that it's "a very strange illness" as some days she doesn't know who he is however he says that when he came in today; "she recognised me". You can see that he has learned to accept that she doesn't always appear to recognise him and is able to enjoy the time with her when she does. As he walks into her room he is surprised to see her awake and compliments her on her hair saying: "Your hair looks nice". She doesn't respond but he instinctively feels the need to repeat himself: "Your hair looks nice today": "Have they paid you?" she says and he laughs reiterating her phrase: "Have they paid me?" He is delighted to get such a lively and humorous response. He is totally aware of her needs and reads the situation.

He goes on to say that he knows her condition will steadily get worse but states that: "There's still something in there" - "When I walked in today - she recognised me", "but it's a very strange illness" - "You can only do so much". "But there's a huge comfort in knowing she's still there, even if she's not the person I've known all my life as my mum"

"In my mum's case she communicates back but in a strange tongue" He laughs a little " She uses random words and sometimes she'll put them into a sentence but it won't be a coherent sentence. It'll have no relevance to what I was talking to her about"

"There's a lot of loving and funny moments - but there's a lot of sad moments with it" He is accepting of her condition and takes pleasure in the small moments of communication he is able to have with her.

TO THINK ABOUT:

What are the barriers to communicating effectively with someone living with dementia?

Is it worth talking to a person who doesn't respond?

MYTH: People with severe dementia can't communicate.

REALITY: They may have lost verbal communication but they can still see and hear and these communication skills should be recognised.

BESSIE WAS A WEAVER

Identity and Respect: Seeing the person first and dementia second

3 sisters sit together every week in a care home. The oldest sister Bessie has dementia but her sister is keen to tell us “Bessie was a weaver”. They talk to her about the work she used to do and Bessie responds by saying ‘I were happy then’.

The younger sister talks about the quality of support in the care home saying: “they all love her and she loves them’. The sisters display great affection for Bessie and talk about her in the present tense; “She’s such a lovely lady”.

They see her as the person she always was, giving her the status and respect she deserves. This is an example of how we need to see the person first and the dementia second.

MYTH:

People with dementia are not the person they used to be.

REALITY:

Behind the ‘mask’ of dementia is the person you’ve always known with their own identity and life history.

TO THINK ABOUT:

How important is a person’s life history in understanding and communicating with a person living with dementia?

How could you support a person’s sense of identity and self esteem?

What does the phrase; ‘seeing the person first and the dementia second’ mean?

SHE'S NO LONGER MY MUM

Voice of the carer, a sense of loss, guilt, isolation

A lady visits her mum who is in a care home for individuals with advanced to severe dementia. She has witnessed her mum's condition worsen over the years from early onset to severe without capacity and is finding it difficult to come to terms with the deterioration and the growing lack of communication. "My mum doesn't communicate so she's not like some of the ladies who say the same thing over and over again. She doesn't communicate at all anymore" She is upset at the realisation that she has lost her mum to this terrible and sad condition but is able to gain some comfort in the commonly used phrase "She's no longer my mum". As a result she is suffering from a sense of loss "it's like I've been grieving for 3 years on a low level".

Added to the sense of loss is a strong feeling of guilt at not being able to do more: "I feel guilty because my mum would have done anything for me and was always there when I needed her". "But I find that my guilt – is about not being there for her more often – and I can't communicate with her - but the staff have been really helpful in saying that it's not your mum anymore and I take comfort in the fact that she's not my mum anymore "

"Sometimes she looks at me as if she's looking right into my soul – and you can see that her eyes are searching – searching for something."

MYTH: People with dementia don't know what's happening around them.

REALITY: Many people with dementia ARE aware of what is happening around them but may not show it. The part of the brain that deals with communication is separate from recognition and this can affect people in different ways.

TO THINK ABOUT:

Is it right for the staff to say that she's no longer her mum?

Why does she feel a sense of guilt?

A DIFFERENT WORLD

The power of music to comfort, to bring joy and evoke memories

A lady is talking to care staff about her school years. She speaks with great clarity and articulation however, as the conversation develops, it becomes clear that she believes she is back at school. Her face becomes animated as she begins to talk about her love of music, the school orchestra and an inspirational teacher. School friends come to mind as she recalls the instruments they played and the happy times they had together. "It wasn't a very big orchestra - but we had first violins, second violins - and we had violas and cellos" – and – "one of the girls was a wonderful pianist"

She becomes slightly disorientated but retains a sense of eloquence as she says: "In my school days here music was the thing that – came through your blood' She then appears to come back to the present as she continues: " Oh music is still very important to me – Oh yes I love music - music's a great part of my life really". The more she talks the more animated she becomes: "It was great because we were all together and we ere all part of this – happy sound".

"It was very inspirational and it lifted you out of your normal day into a different world."

MYTH:

People living with dementia can't remember the past.

REALITY:

Dementia affects short-term memory but often a person's long-term memory is very good. Music can be a positive stimulus for evoking the past.

TO THINK ABOUT:

How can music be a sense of comfort and support for people living with dementia?

How can you identify the music preferences of the individuals you are caring for?



Music In Mind is a registered charity to promote the use of music as an aid to public health and well – being, learning and creativity. Innovative projects and performances use music and the arts to raise awareness around important social issues and give a voice to the seldom heard.

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