

MUSIC FOR PEOPLE LIVING WITH DEMENTIA

Ruth Bright, AM, DMus, Registered Music Therapist

The Challenge of Dementia

Dementia is a major challenge to society, and - as we live longer - there will be increasing numbers of people whose memories have 'let them down'. We may imagine that everybody thinks the same about the occurrence of dementia in a family member: first disbelief, then shock, disappointment, anxiety, sadness at the loss of an active relationship, fear of the future. Often too there is guilt in recalling irritability and anger over inexplicable behaviour - which later proved to be a fore-runner of dementia.

Although these are common, people's responses are in fact not all identical. We need to know that not everyone feels the same; some people are desperately ashamed and some may even feel superior about it. And, if a marriage has been marred by constant abuse, the unaffected partner secretly thinks "Huh - serve you right!" - now it's my turn to push you around!"

Cultural aspects of dementia

Our cultural background also affects our attitudes, and by 'cultural' I do not mean matters connected with music, art and literature, but the mixture of race, country of origin, general education and social upbringing which moulds the way we behave, think and feel.

In some groups, such as traditional Aboriginal people, dementia is seen as a form of insanity, perhaps even a punishment for wrong-doing. In any nomadic group, people with dementia or any other major disability may be abandoned because the tribe cannot cope with those who are unable to walk, unable to eat normally and so on. I am not aware of that happening in Australia today, but it was a feature in the past. And even if people with dementia are not abandoned, attitudes towards them may be coloured by past beliefs. (The same is true of other disabilities, especially in the new-born, in Aboriginal people and some people of European origin.)

We know that there are many different causes for dementia:

- Alzheimer's disease (the most well-known cause)
- Vascular dementia - resulting from several strokes (previously called Multi-infarct dementia)
- Damage to the brain resulting from alcohol misuse
- Damage to the brain resulting from substance misuse
- Damage to the brain resulting from acquired brain injury (e.g. car accident, surgery)
- Lewy-body dementia (this is especially confusing because it often causes visual and auditory hallucinations)
- Huntington's disease
- Frontal-lobe, fronto-temporal lobe dementia
- Sometimes in multiple sclerosis
- Sometimes in Parkinson's Disease
- And others!

What do they have in common? You probably know the answers to that, but we need to remember that not all dementia is the same and not all people behave in the same way. We are all individuals! But importantly, creative arts, especially music, reach *almost* everyone!

MUSIC

Music affects different people in different ways, and cultural factors are crucial to the way we interpret what we hear.

- some people prefer classical music
- some people relate only to the traditional music of the homeland
- others prefer church music
- some people care only for the latest "hits",
- Research shows that, in general, we only understand the meaning of music from the culture with which we are familiar. [Bright 1991]

Although there is a universal interest in music, there is no universal music! (We can see this when a group of people describe their personal responses to an item of music - people's associations differ widely.)

But what we are considering today is the value of music to people living with dementia. Music is spared even when other aspects of memory are lost, and the world-famous neurologist, Oliver Sacks told me that he believes this is because music is 'multi-wired' in the brain, not restricted to a single area.

My own observations suggest that we deal with music in various ways, both intellectually and emotionally, and here the three categories of memory described by a group of American neuro- psychologists are relevant: declarative memory, procedural memory, and familiarity (the non-verbal sense of 'knowing'),.

1. Using declarative memory, we recall, and state, the title of a piece of music that we hear.
2. Using procedural memory, we tap our feet, clap our hands, move in time with the music.
3. In familiarity-type memory, we feel that we somehow know that piece of music, without knowing its title. [We all do this sometimes!]
4. We may recognise the emotional content with which it was imbued by the composer, either influenced by the title that was given to it or by the nature of the music.
5. We may remember and respond emotionally to events linked with the music, (NB These may differ from the composer's focus).
6. The professional musician may listen analytically, noting the instrumentation and style, thinking about the structure, the date of composition and the nationality of the composer.
7. We may or may not notice incidental music played as we walk into a theatre; a student may put on a CD or tape as background music while studying, apparently paying no attention at all to the music!

Some of these responses involve our emotions:

- * We may feel triumphant that we were able to give the title of the piece when hearing it by chance on the car radio or in a shop!
- * We may feel sad on hearing the song which a recently-deceased relative used to sing to us in childhood, or the tune to which we danced with someone who is now gone.
- * We may experience feelings of horror if, as a survivor of Dachau, we hear the music which was played while our fellow-inmates were led to the gas chamber.
- * Without any conscious intention, we react to the mood music of a suspense movie

But dementia, whatever the type, is progressive, and we cannot make blanket assertions about what people can or cannot do! Thus, although we know that music is spared in dementia, it is only in the early stages of the condition that major creativity remains or that people can ask for a particular item of music.

What we see in advanced dementia, when music is played which the person used to know, is a sense of familiarity, and it is this familiarity which is so important in communication.

- ✓ The person can often recall the words, even perhaps reminisce about why it is familiar
- ✓ But even if those responses are impossible, the face usually becomes alert and focused on what is happening, often with a smile but sometimes with tears
- ✓ Shoulders, feet or fingers may move in time with the music
- ✓ All or some of the words of a song may be sung
- ✓ There may be a verbal comment, "That was lovely", "Oh yes!" (= I know that!)
- ✓ Eye-contact is made with the musician and with others nearby who are part of the interaction.
- ✓ Most important of all, the loving onlooker sees - for a few moments - the awakening of the personality they once knew.

This opening of a window is important to both relatives and staff. We hear comments such as:

- ❖ "Isn't it wonderful - she used to sing that to us kids!"
- ❖ "He's still there!"
- ❖ "There is more in her than I'd realised"
- ❖ "I wonder whether singing to her would make her less difficult to shower in the mornings?".

Relatives experience mixed feelings:

- ◆ Happy that the person can still respond - yet sad that the response is elicited by a stranger and not by themselves
- ◆ Glad that the window of communication opens, however briefly, yet distressed because the opening of that window makes them realise how much change has taken place.

As a professional therapist, I am aware of feelings that are often hidden below the surface and try to help relatives to deal with these by acknowledging them openly.

I usually start by asking whether they remember music that the client used to play, sing or whistle. "Did your dad whistle while he swept the front drive?" (or similar remark appropriate to family background.) or "Would you be able to sing that Lullaby you told me about, while I play it? It would be great to make this a threesome!"

Then, when an atmosphere of trust is established:

- ✓ "It must be difficult for you to see your Mum responding to the music like that, when she can't remember who you are..." (Or "...when she is cross with you for not coming - even though in fact you come every day.")
- ✓ "It makes you realise, doesn't it, how illness can change people, when you see someone - who seems far away - come back to how they used to be, even if only for a few moments "

Sometimes one is astonished by verbal responses, such as the woman who said:

"The music is wonderful - it is like coming out from under a wave and finding there's life left in you yet!"

Another resident, who has memory loss for every other facet of life, asks me each week to play "Jerusalem" for her, and sings the words.

Sometimes the responses are non-verbal, like the woman, apparently unconscious and within an hour or two of death, who swayed her shoulders when I stood beside her long chair and played her favourite waltz - then opened her eyes, smiled and mouthed some of the words. (Her daughter, sitting with her, was much moved by this.)

The response is not always smiles and happiness: because of personal associations, music can elicit painful memories too, or can bring some measure of awareness of what has been lost.

How do we deal with this?

NOT by changing to happy-clappy music, nor by saying "Come on, Cheer up - life's not that bad is it!"

What we do is to acknowledge the sadness, even if only by the touch of the hand. But words can help - and even if the meaning of them is lost, the tone of voice had meaning.

"Life is really difficult for you, isn't it..... Things can be really tough ... but you're still a person, you know - and people still care about you!"

A hospital patient, speech usually lost in a jumble of syllables, patted my hand as I spoke to her in this way and said "Nice you say!"

Ideally all nursing homes and facilities for persons with dementia would employ a music therapist, who is trained to deal with people at different stages of deterioration, trained in relationships with visiting relatives to help them cope with what are often painful situations - especially difficult when the previous relationship between, (e.g. adult child and parent) has been a difficult one.

The music therapist is also knowledgeable about appropriate music for any given age group and any given culture, with a repertoire of world music that can be played on request. (Or can obtain a requested piece if it is not immediately familiar to the therapist - which does happen!)

But registered therapists are not always available. So what can staff and volunteers do to use music in a helpful way?

Even when a full-time music therapist is employed, there are times when he or she is not available.

- Bathtime
- Dressing
- Changing clothes after an episode of incontinence
- Walking to meals
- Leaving the dining room
- And so on.

Singing during daily routines: my 1985 research, included in my book on dementia, (Bright 1997) showed that many nurses find that to sing with difficult patients reduces aggressive behaviour and encourages co-operation. I notice that some people who resist personal care are misinterpreting what is happening because they do not realise that they need help with hygiene etc. one woman who punched, screamed and kicked nurses who undressed her for the bath was, I came to believe, seeing their actions as sexual assault.

To sing familiar music (even if you don't sing well!) gives an air of friendly intimacy and defuses the fears arising from lack of awareness. (You could even take a tape or CD player into the bathroom with you if you don't have the courage to sing alone!

(Although poetry is only somewhat connected with music, I do recommend the work on poetry being done in Stirling (Scotland) University's Dementia Service by Jon Killick who is their Poet in Residence. Many of the poems written by people with dementia have been published, e.g. .

'You are words: Dementia poems', edited by John Killick.. Reprinted in 2000 by Hawker Publications Ltd, 13 Park House, 140 Battersea Park Road, London, SW11 4NB. Fax: (0015) 44.20. 7498.3023

SUMMARY:

Common features of the use of creative arts in dementia

I believe strongly that it is OK to work with people who are living in the past without trying to force them into the present, whether we are using music or one of the other art forms.

At one time there were attempts to insist that people should be orientated in time and place, know who was talking to them and where they were, what day it was and so on. This was called Reality Orientation and we were all pushed into believing that this was The ONLY Thing for People With Dementia..

Thank goodness it fell into disrepute and it is now OK to let people feel a bit muddled!

So now it is OK when one of the ladies says to me (after I have played a song her father used to sing): “O yes, my father sings that every day, you can hear him down the street – he’s a wonderful singer, I don’t know how he does it! And I go and help him each day so that he gets things done a bit quicker!”

I respond with some hint of the past “O yes, he was a baker, wasn’t he?” but she usually misses the significance of my use of the past tense, and continues to tell me – in the present tense! – about her daily life in a small country town in Queensland.

A very elderly man used to try to force his way out of the locked door of the dementia ward at one hospital, saying desperately “I’ve got to get home – my mother will be worrying that I am not home from school yet.”

To this I used to respond “Tell me about the food she used to have waiting for you when you got home?” This distracted him effectively from his frantic struggles to turn the doorknob, and (although he used to veer between “She does this or that” and “She used to ...”) the changes in mood and the relief from anxiety lasted quite a while.

Spiritual needs

Carers do not all have the same level of spirituality, but it is vital to be aware that people with dementia do not lose the spiritual feelings which they may have had all their lives, and we need to help them to express these through familiar hymns, Sunday School Songs or prayers. (I find that they often remember the words better than I do!) This music frequently elicits happy memories as well as present faith and trust, and the music is usefully supported by appropriate art works. (But choose carefully – some religious art works are not acceptable to every individual.) The feelings which come to the surface may be deeply emotional.

Expressing emotions

The creative arts, and especially music, reach deep into the heart and may elicit feelings of which we are otherwise unaware. This may be expressed through tears, anger, or other emotional behaviour.

We should not be afraid that anger may be expressed as part of reminiscence: if we try to pretend that life is easy - that is just what we are doing – pretending!

Also we should not be afraid of tears, but accept that life can indeed be sad and scary if you have lost track of everything, lost the skills you used to have, lost people through death, illness or accident, perhaps lost your familiar home, and so on. Someone may also recall old losses – even the stillbirth of a baby - two generations ago, a son who went wrong and ended up in gaol, a marriage which was unhappy, and so on.

When the tears and grieving have gone on for a few minutes it is OK to distract the person – even the proverbial cuppa can do it! **Not** by saying “*Now, come on, that’s enough – let’s talk about something happy!*” but by using distracting techniques – “Tell me about the schools your kids went to” or similar comments which distract – but without giving the person a feeling of being disapproved.

Dementia is not easy, for *anyone* living with the condition. But music may re-awaken old, lost relationships, and help to make life more interesting and more enjoyable, for all those people who are living with dementia .

PRACTICALITIES:

If you are not good at singing, don't worry – to have live music is helpful++ in creating a sense of intimacy, and even if you are not very good at singing, it will still 'work'!

But if you really have to use recorded music, there are some 'musts':

- (a) Be sure the music is familiar – choose something from the past life of the family, a show you went to together, a Musical that you enjoyed on TV. If all else fails, look at the Copyright date and choose a song that was popular at the time the person was in early adult life. It may not be the favourite, but it will be familiar..
- (b) Only play one item at a time, then stop and talk about it – “Do you remember when we....” Then play it again - and again, if necessary! But NEVER leave a tape/record/CD to run on and on, one piece following another without a break!
- (c) Always be present while the music is playing so that it is a means of communication not of entertainment. (There may be times when you put the disc in and go off to the kitchen to do something urgent or answer the phone, but that makes it difficult to keep the person concentrating on the music.)
- (d) You may be able to find appropriate music in various ways – see below, in Resources.
- (e) Most important of all: If possible find a way of giving people the chance to choose. Even if someone cannot recall the name of a song, you can suggest two - and ask which they would rather have. The answer may well be at random rather than a true decision, but one gives the person the courtesy of offering choice, the chance to decide something independently.

Resources of music

1. Look in cupboards for old hymn books, old song books etc.
2. Ask your friends and neighbours whether they have old songbooks. (The 'Readers Digest' produced an excellent range of books containing popular music of different types, with details as to when the pieces were first performed - very useful in leading conversation about old memories!)
3. Go to local fetes and look on the white elephant stalls.
4. Get a paragraph printed in your local paper – you will be surprised what turns up!
5. (You may not read music but the sight of the words will help you to recall the tunes!)
6. If using recorded music, avoid tapes because it is difficult (impossible?) to pick the tune you want on a tape. Use CDs whenever possible because they enable you to select the item you want without difficulty.
7. To purchase new CDs of old music, go to the web site: www.entertainmentmasters.com.au On that site you will find a huge array of music from all eras, with costs etc all listed – don't forget to check on the postage costs too!
8. But if using records, don't forget items (a) – (c) above.

References

Bright, 1991. Chapter on "Cultural Influence in Music Therapy" (a research report) , in "Music Therapy in Health and Education", ed. Heal N, and Wigram A., Pub: Jessica Kingsley, London, 1994

Suggested reading material (These items may be in Libraries)

Care-giving in Dementia: Research and Applications. Edited Jones & Miessen. Published Tavistock-Routledge, London, 1992, Chapter 10, by Bright, is about music)

Ruth Bright, Music Therapy and the dementias: Improving the Quality of Life. (2nd edition) 1997, St Louis, MMB

Ruth Bright, Wholeness in later Life (1997) Jessica Kingsley, London

Ruth Bright, Supportive Eclectic Music Therapy in Loss and Grief 2002. (Pub: as above)