Music Mirrors: Practice-based reflections on the development and uses of audio biographical cues to support people living with dementia and other long-term conditions

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ABSTRACT
This article is a practice-based account of the development and use of a person-centred digital resource called 'Music Mirrors'. This approach was developed by the author, who works as a community musician with people living with dementia, their carers and families. Making a Music Mirror is a simple but effective way of capturing key biographical links with sounds and music that are a significant part of the soundworld of a person living with dementia. When used sensitively within an ongoing personal relationship (with a carer, family member) a Music Mirror offers the possibility of finding and sustaining bridges of communication and understanding otherwise threatened by cognitive decline. Recently the idea has also found interest within other social care and health fields where people are struggling with cognitive challenges and their effects. The article gives a personal account of the 'discovery' of the idea, its practical applications, and discusses its implications for using music within person-centred care in terms of opportunities and challenges. The article does not aim to discuss current research but touches on the important difference between the Music Mirrors approach and the currently more popular 'playlist' approaches.

KEYWORDS
Dementia; person centred care; digital music resources; biographical cues

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1. INTRODUCING MUSIC MIRRORS

M, a woman living with early-onset dementia, had arrived upset and frustrated at the day centre. Spotting her distress, a carer quickly came to meet her, saying: ‘O but you’re just in time for the singing, and if you’re Welsh you can’t help singing, can you?’ Within seconds M’s face visibly relaxed, she smiled, nodded, agreed to come in and settled into the group. The reassuring greeting used words from M’s Music Mirror, which, a year earlier, M herself had helped to make. Recognising her own familiar words functioned as a way to break the loop of distress and anger clouding the morning so far, and paved the way to her involvement in the singing activity, an activity which had always been central to her life.¹

Dementia often brings special problems of creating and sustaining understanding between carers and those being cared for. As time goes on, communication can become difficult, making it harder to know and reach the person still keenly alive behind the symptoms. This can lead to misunderstanding, stress and isolation. This is where the Music Mirror can help. A simple person-centred resource it consists of a few written lines of biography or familiar words, with cues of sound and music embedded to spark associations. Made with and for vulnerable people and used with the support of a second person, it provides material to comfort and build bridges of understanding. A Music Mirror can be written on paper, or stored digitally with links to recorded sound or music via YouTube and easily accessed via the familiar technology of iPad, tablet or smartphone.

What follows is a personal narrative of how Music Mirrors came into being, with reflections on their use. My hope is that it may give insight into practical approaches to care within dementia, end of life and mental health - areas of increasing interest within health and social care research.

2. HOW MUSIC MIRRORS DEVELOPED

The concept came from my experience of caring for a family member and of leading singing and music sessions for people living with all degrees of memory loss. In 1998 my father had a major stroke compounding multiple-infarct dementia. After four years in care and with very limited communication, his quality of life started to improve significantly and he began sometimes to speak fluently and coherently. The change began after I found and began reading from a notebook of stories he had written about his earlier life. Episodes of speech often followed or seemed in response to hearing these readings of his own words, and in his last two years the moments of communication clearly meant a great deal to him as well as to my mother and me.

In 1998 I helped to set up a small voluntary organisation providing therapeutic singing and music sessions: as community groups, in day centres, care homes, acute general and dementia hospitals, and in palliative care. This brings the privilege of knowing some people throughout their time with dementia, and of seeing how music can help them continue to connect as individuals with others around them. I also learned how hard it can be to unlock more than just a general response without a personally meaningful key, even when someone is clearly receptive to music. This is a recognised issue in residential care, where there is

¹ Observations from the author’s practical experience.
often not enough access to biographical information about people, as Miesen (1992) comments:

It was very difficult to start any type of work with them (people with dementia) because there was simply no information available about their likes, dislikes, special avocations, life history or the circumstances that had led to their permanent institutionalisation, and, as verbal abilities and comprehension diminish, it becomes difficult to collect such information from residents themselves. For example, when playing music for someone, it took a long time to discover their favourite songs, melodies and types of music because this sort of information was not collected in the traditional medical notes. (Miesen, 1992, p.101)

Music Mirrors grew from awareness of this gradual erosion of identity which, with each successive change - falling-away of family and friends or physical setback - makes it harder for someone to be and to feel recognised as an individual. Simply: each of us is the sum of our own individual memories; sound and music help us remember things, from mother love to times tables; memories can fade - it is a natural part of ageing but can happen through accident, illness or dementia; one should capture them now to take with us into the future.

My initial idea in 2013 was to talk to people with early memory loss, capture and write down positive memories and link these to recorded sound or music to be stored for the future. The concept took digital wings a few weeks later with the thought of writing the memories as emails and embedding the auditory cues as links to recorded music on YouTube.

3. What A Music Mirror Is And What It’s Not

Many people with dementia experience problems with behaviour and mood, often made worse when speech and communication are difficult. Stimulation is often recommended instead of medication to lessen distress and agitation, and in recent years various musical interventions have been explored (music therapy, singing, Singing for the Brain, individualised playlists of recorded music and other initiatives).

A Music Mirror is somewhat different in being a written resource: not an end in itself but a kit of tools to be used according to need. It can be stored simply on paper or made digitally portable for use and sharing via familiar technology. In this it differs from life story books/boxes or playlists which may rely on personalised equipment or tangible objects.

It is not a bespoke playlist of preferred music. The pleasure and benefits of much-loved music are well researched, but playlists are not a panacea. Music’s impact can vary from day to day, and the distress of someone left listening to a playlist unsupported may go unnoticed by well-meaning carers who assume that they are happy and content. Isolated, wearing headphones or alone in their rooms, vulnerable people may be unable to stop the music or alter its sequence or content. They may experience the same kind of depersonalised care as the old ‘chemical cosh’ or wall-to-wall television. This is clearly not the intention, but the scope for misunderstanding can be seen in a report on the ‘Power of Music through personalised iPods’ commissioned by the Alzheimer Society of Toronto which says that providing personalized music through an iPod to people with Alzheimer’s disease and other dementias helps to calm them and reduce their
anxieties and fears, while providing their caregivers much-needed respite to focus on daily household tasks or their own personal needs (emphasis added).

In contrast, Music Mirrors encourage personal contact and social inclusion, giving starting points for engagement rather than material for entertainment or listening alone. Mirrors capture brief clues, typical turns of phrase, favourite topics of conversation, sounds linked with upbringing and culture, in order to help build constructive relationships of care and the sustaining of identity. Short anecdotes give practical openings for reminiscence or other therapeutic interventions, and the added layer of familiar sound or music may reach and engage when speech means less. Digital portability gives easy access to person-centred material at times of change, transition or anxiety when people need quickly to be put at ease.

In the UK, Music Mirrors are currently used in domiciliary care, residential homes, acute hospital settings, by allied health professionals and as support and advance care planning after dementia diagnosis. Befriending organisations, sheltered housing complexes, Women's Institute, libraries and arts organisations have requested training for community workers and volunteers. In the UK a Suffolk NHS community mental health team meets regularly to share insights from their practice, and awareness is growing of the potential as legacy work with younger patients in palliative care. People are beginning to come into care and hospital with Mirrors already made. In September 2017 the Center for Gerontology and the University Research Priority Program (URPP) Dynamics of Healthy Aging of the University of Zurich began a four-year intervention study devoted to the making and using of Music Mirrors within Swiss dementia care.

4. MAKING MUSIC MIRRORS

A Music Mirror is usually made at the instigation of a family member or someone aware of their own need for advance care planning. Sometimes I have previously known the person, perhaps through a singing group, but not always, and it is important to be sure that the project of making the Mirror is well understood and welcome. Typically I explain a Music Mirror as a soundscape of one's life, describing how something similar helped my father after a stroke, and say that I have already made my own.

Jack had been referred by a post-diagnostic support group and had talked with his wife beforehand. He was happy to chat over a cup of tea, and in conversation his words themselves were as important as the information they conveyed: “My mother said 'It's about time you got our Jack some pigs!' so I had some myself. They were Gloucestershire Old Spots.” Here both key memories, of his mother's words and the sound of pigs, were gold dust. Later, in a lull in the conversation, he asked: “What's your name? 'Eather? I've can't say my aitches because I come from Gloucestershire!” From that we accessed recordings of stories in Gloucestershire dialect which gave him great pleasure. Memories of dancing and the local picture house also yielded many musical links.

The following excerpts show how a Music Mirror may look:

“I grew up in a small town called B..... and we kept chickens at the top of

2 All excerpts used in this article are with permission.
our garden. I remember having to go and say goodbye to the cockerel (always called Horace) every year before we ate him at Christmas time.”

“When my Dad and I cycled to my Nanny's ... if I got too far behind on my little bike my Dad would stop and sing ”when I'm calling you” and I would always answer him by singing, ”I will answer you” and catch him up.”

“I use to spend a lot of time with my Nanny whilst she cleaned the Methodist Chapel. I was allowed to pump the organ pedals and pull the stops out. She taught me how to play All Things Bright and Beautiful and we use to sing it as we polished the wood in the Chapel.”

The resonances of time, place, emotion and personal attachments in these few short sentences of this Mirror have potential to trigger a whole wealth of further memories and feelings. The associated sound or music then brings the experience to life even more vividly.

Making a Music Mirror with support from an empathic listener can in itself be very positive and the outcome a matter of pleasure and pride, to be shared with family and friends. Done with care, it is valuable person-centred post-diagnostic support. As a volunteer who made one of the Mirrors commented:

“... when they found out it was so personal to them, they couldn’t believe anybody would give them so much time, and give them so much input into something that was going to stay with him hopefully for the rest of his life and would always be accessible.”

“They were really happy with the making of the mirror and talking it over... It was like building up a friendship. They feel like they’ve had a little bit of special treatment, I’m sure they do. I wish we could do it for everybody.”

Making a Music Mirror depends upon the sensitivity of the helper, and her/his ability to note often subtle and brief clues. It also requires great care in writing these up accurately. A Music Mirror may also flag up things that distress, annoy or infuriate someone who can't easily express this: a fear of the sea, music with unpleasant associations. Such small clues may make a great difference in easing the stress and frustration of daily life for both carers and cared-for.

A perceptive helper, for example, linked a resident's memories of his father's convivial songs to others of his fear of hearing his dad coming home drunk. From this the helper was able to draw attention to a potential trigger for negative memories - familiar songs which might easily crop up in reminiscence sessions.

The conversation is best held in familiar surroundings, whether the family home or one’s own room in residential care. Peace and quiet are essential, but it is best not to move around directly before starting: going to a different room can disrupt and give the feeling of an interview rather than a relaxed chat, subtly skewing responses.

A ‘Thinking back…’ leaflet given beforehand suggests topics for exploration with family or carers. This is not a tick-box questionnaire intended but to leave ideas
‘in the air’, ready to come up naturally in conversation. At home, pictures, books or other belongings often provide additional openings.

The role of helper in making a Music Mirror is crucial: sympathetic interested facilitator, note-taker, responsible for capturing words briefly but accurately to reflect their original spirit and meaning, and later matching memories with sound and music. Genuine warmth and interest are essential and unbiased willingness to follow the lead of the person with memory loss while watching for topics that appear to cause real distress. The ideal is to take the four or five most positive, vivid memories to link to sound and music: a Music Mirrors needs to be brief for use in busy environments.

A Music Mirror aims to capture moments that really matter: hard enough at any time, let alone for someone with memory loss. Direct questions - ‘do you remember, what did you…?’ - can challenge and inhibit: it is better to explore feelings and experiences, listening for special words or turns of phrase and with an ear for links to sound or music. Taking time is essential: some of the best insights come when the conversation seems to be treading water.

Families can make Music Mirrors with relatives, but it is often better done by someone with ‘fresh ears’. Family can help, but are easily tempted to act as ventriloquists and, over-eager or embarrassed at the slowness of response, may inhibit genuine input as their relative then often finds it simplest to agree. Partners or children may have a quite different view of life lived together, little knowledge of childhood memories, and suggest currently preferred music rather than things with deeper roots. Being so close can also mean not spotting things which an outsider would see as obvious Music Mirror material. Stories thought long forgotten often surface spontaneously in conversation with a new attentive listener.

5. How Music Mirrors Are Used: Examples and Reflections

Music Mirrors have many uses. Although originally devised for people living with dementia they can help other vulnerable groups in mental health, palliative care, learning disability, residential care.

The following examples illustrate their use in dementia.

"It was a little late for M to have much specific input into her own MM, but we talked about music and I worked from her husband's clues and by observing her responses to my guesses - Welsh hymns, Schubert lieder, early music, etc. One thing however stood out: she returned repeatedly to the memory of protesting as a child: ‘I’m Welsh, so I can’t help singing!’ I described at the beginning of this article how this helped later at a day centre: recognising her own words reassured M and reminded her of her love of singing, but also gave her back the vocabulary to say yes to a pleasure denied her by the illness. Staff reported eliciting the same response on several occasions."

M’s daughter has written:

“I’ve been amazed by the power of music to help my mum escape from the agitation and frustration that is part of her dementia... She has always

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6 Observations from the author's practical experience.
enjoyed music and used to sing in choirs when she was younger. Now, just hearing the introduction to a familiar song instantly seems to take her back to the competent, capable, authoritative personality underneath. Her face lights up, the previous irritability melts away and she starts singing, remembering all the words, and knowing (I think) that she’s good at it.

My impression is that she is spending much of her daily life now searching for what she ought to be doing, or what her purpose is, but never finding it. The key has been to find out which tunes or words are relevant to her. Music Mirrors create a personal “bank” of songs which trigger her memory, and once identified, these can be used by anyone to help her return to a world she’s familiar with. Listening to music also helps her to relax but it’s the active mental and physical engagement of singing that really lifts her self-esteem and mood in a way that nothing else can.

My mum used to be an English teacher and she still has a strong interest in language and poetry. Short snippets of familiar poems, puns, or amusing use of language stimulate her and help trigger her vast long-term memory stores. As a teenager, I spent most of my time ensuring that I ignored everything she said, but I can now see that by listening to her favourite phrases and reflecting back her own use of words, it’s possible to create a positive atmosphere which allows her to communicate almost as if she didn’t have dementia. Again, once a few meaningful phrases or lines of familiar poetry have been identified, anyone can use these to create a connection where she is able to be in control.

She is understandably frustrated and angry about being in a care home, and unfortunately the reaction of staff is often to prescribe drugs to try to reduce her distress and make her more manageable. Last week I watched her mood change in seconds from agitated anger to perfect calm after starting to play just a few notes of one of the many songs she knows. I really wanted the staff to see this to understand the power of non-pharmacological strategies.

C had been a band leader. He identified strongly with the songs and musicians of his youth yet showed little interest in hearing the music itself: his memory was primarily of the physical act of drumming rather than of being a listener. His wife described his delight with the written transcript of our conversation which he carried with him for several days and showed proudly to family and friends. The completed Music Mirror interested him less: the recorded music perhaps had less connection with his sensory memory of music-making and identity as the leader of the band?

B’s wife doubted his ability to contribute much to his own Music Mirror, but in conversation he revealed a life full of memories associated with sound or music. His father and brother had been musicians but B himself preferred sport, especially golf, and with his wife had travelled the country scoring golf tournaments.

Later his condition suddenly worsened and B, acutely agitated, was admitted to a dementia intensive care ward. Searching for clues of any kind to calm him, staff

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7 Observations from the author’s practical experience.
asked for his Music Mirror, possibly without much hope. Some months later at a post-diagnostic support group I heard a nurse describe how ward staff had used a Music Mirror to distract a distressed patient, unmistakably B, by playing the sound of golf balls close to his ear! Having captured his attention for a moment, they later used other music he loved to soothe and comfort him. The nurse now advocated making Music Mirrors at an early stage.\(^8\)

\(J\), proudly Geordie and an enthusiastic singer, was admitted to hospital after a major stroke, very unwell and unresponsive. Her daughter asked me to visit and sing with her, and when this produced smiles, speech and expressive body language her Music Mirror was emailed to the ward. Dementia support staff then used an Ipad at the bedside to access songs familiar to her and information about her home in the North East.\(^9\)

A dementia support worker later wrote:

> We were able to support a lady who already had a music mirror when she came into hospital. By accessing the links of familiar and meaningful songs of hers played on the Ipad, we saw the effects of this were very positive, it could be seen clearly that the individual was physically affected by the music. She engaged with the music mirror by expressing herself through positive body language and humming along to the music, managing some words. The family believe that as a result of these visits with music the individual’s wellbeing was significantly improved. This in itself proves the effectiveness and importance of music mirrors.

After J’s death, her daughter wrote that the Music Mirror had been ‘a glow of connectivity in my last weeks with mother’.

\(S\) had spent life playing string quartets and going to concerts, and her room was full of records, scores, programmes and musical memorabilia of all kinds. Now however, sensing that her concentration was limited, she felt that listening to Beethoven would be an insult as she could no longer fully follow his thoughts. She explained this carefully, taking time to find exactly the right words. I asked if it felt a great loss, but she said quietly no, she was used to it, adding wistfully that she ‘would like to walk past a room where quartets were being played’.\(^10\)

In each of the examples above the Music Mirror has a different use. With M, it allows a second person to mirror her own words, so that she can say yes to a much-loved activity which lessens her anxiety and frustration. With B a startling but familiar sound in an unexpected context momentarily distracts him from acute distress. Having gained his attention, staff have chance to help him ‘reboot’ before moving on to other ways to soothe and reassure him. A Music Mirror gives support workers of quite different background access to songs which are part of J’s cultural identity and childhood, and they can encourage her efforts to engage and respond. V craves the physical memory of youthful strength and freedom to

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\(^8\) Observations from the author’s practical experience.

\(^9\) ibid

\(^10\) ibid

\(^11\) ibid
balance the daily restrictions of being housebound and dependent on carers. S on the other hand recognizes and accepts that her life has changed but longs for a vital snatch of 'her' music to sustain her identity and sense of value as the musician she used to be. C, the bandleader, arriving angry and upset at a support group, could often be cheered and distracted if greeted as 'the Ding-dong daddy from Dumas', the hero of one of his favourite numbers.

The words in Music Mirrors are vital, capturing identity, giving context to the auditory cues and more. Catchphrases, nicknames or ways of saying something will later give an idea of background, sense of humour, manner and the way in which one would wish to be recognized. A familiar term of endearment can make someone feel loved and accepted. The aim is not a coherent life story narrative but a collage of unique verbal snapshots: for my father it was the mention of 'ralleyvo' - a street game - which prompted speech after four long years.

What is described above is not consciously preferred music but auditory and verbal cues which could be described as visceral: things that were simply 'around' as physical, unchosen parts of life rather than elements of a constructed identity. A questionnaire would not easily tease them out. They surface when least expected: a ragbag of the words, background noise and incidental music of a lifetime. It is this which sets Music Mirrors apart from the individualised playlists of music in initiatives such as Playlist for Life. The additional access to familiar language describing the context of memories of sound and music has the potential to recall and bring alive identity, culture and a sense of the past not just for the individual but for those caring for them.

6. RECEPTION OF MUSIC MIRRORS

Music Mirrors evolved through the various personal contexts of working as a musician (piano teacher, lecturer in music, leader of music groups in Norwich). Having made my own Mirror I tried them out with members of the singing groups with encouraging results: people seemed to enjoy both the process and the outcome.

At first I had no connections with health organisations, so development began very much as a 'bottom-up' process through local contacts.

Initial support came in 2013 from Norfolk and Suffolk NHS Foundation Trust (NSFT). Under their aegis I developed and ran training workshops across Norfolk and Suffolk for around 250 NSFT staff, healthcare professionals, psychologists, formal and informal carers, voluntary organisations and arts professionals, and presented Music Mirrors at major UK and European conferences. University of East Anglia worked with NSFT to refine the concept and develop research funding bids. Norfolk and Norwich University Hospital (NNUH) trained dementia support staff and dementia links to use MMs and patients can also be referred for help in making MMs to use after discharge. Other hospitals locally have also had staff training. A BBC Look East in 2014 (available on www.musicmirrors.co.uk) promoted understanding, awareness and interest. Millennium Forum Library in Norwich offers a self-referral service for help in making Music Mirrors.

After becoming part of MyBrainBook, a digital self-management platform developed by Ixico for people living with dementia, Music Mirrors own (and originally very basic) website was expanded to include a database for profiles to stored for free with confidential password and retrieved wherever needed. In 2016
South London Health Innovation Network (HIN) promoted free Music Mirrors training and awareness sessions across South London for Clinical Commissioning Groups, care homes, hospitals, voluntary organisations, libraries and arts and other groups. The outcomes are summarised in: http://www.hin-southlondon.org/resources/music-mirrors-report and in Journal of Dementia Care in June/July 2017. This campaign was shortlisted as finalist for the prestigious Guardian Award for innovation in mental health services in 2017 Advancing Healthcare Awards. Links with the University of Zurich led to a four-year intervention study of Music Mirrors.12

The project itself is very low-budget but since 2014 has received generous funding of £6000 from the Brief Community Fund via the Norfolk Community Foundation.

7. TRAINING OTHERS TO MAKE MUSIC MIRRORS

Positive reception of Music Mirrors, and their potential for use in medical and social care contexts brought the need for training in making them. Workshops developed in sessions for NSFT and HIN (2012-2016) guide participants in exploring for themselves the link between sound and memory, and end with a practical taste of making a Music Mirror with a partner. Assembling and sharing the Mirror, complete with Youtube links, with partners afterwards helps to give participants confidence to try out the idea in their own practice.

A written manual and printed resources, regularly revised in response to participant feedback, underpin the training. These outline the various stages of talking, transcribing, double-checking, choosing and assembling links to make and deliver a Music Mirror to a vulnerable person and their carers. Further resources developed with HIN and technical advice are available on the website www.musicmirrors.co.uk

Trainees must always be reminded that this is not a life story or a playlist of preferred music. A Music Mirror is a toolkit: scraps of words, sounds – and music – which hold real meaning for an individual and which may support person-centred care.

8. MAKING MUSIC MIRRORS WITHIN RESIDENTIAL CARE SETTINGS

Gathering material for Music Mirrors is best begun early, but although it becomes more difficult with time, especially after moving away from home, it still can and should be done. Care home residents are sometimes admitted to hospital or attend out-patient clinics, and this can be upsetting, disorienting and challenging, even if a trusted carer is present to help build bridges with new people and surroundings. Hearing just the right word or song can help to put people at their ease in unfamiliar environments if they find it hard to speak for themselves.

Housekeepers and hairdressers in care homes often spend quality time and build close relationships with residents, perhaps because they are not carrying out personal care or seen as authority figures. By involving everyone - whether working or visiting - in collecting key words, catchphrases or favourite memories, personal insights can be collated by the person tasked with compiling Music

12 http://www.zfg.uzh.ch/de/projekt/Musikspiegel.html
Mirrors and added to individual care plans. The whole home then becomes part of the listening process, valuing not just the residents but the contribution of all who know them.

Work so far with two care homes has been encouraging. Carers have welcomed insights to help them to put residents at their ease: knowing that someone struggling to accept personal care will relax if the carer sings 'Stand up, stand up for Jesus', or that someone else was involved in a ferry disaster and is terrified by the mention or sound of the sea. The limitation is the need for a scribe or project worker to collate material and assemble the Music Mirrors. Care home staff and families have been willing to contribute and see the benefits for both residents and themselves, but they may lack time, confidence and skills to complete the MMs. Activity coordinators often have other time pressures, so this is an ideal role for a volunteer or project worker.

Family input can be invaluable at this later stage. Some have described helping to make a Music Mirror as a positive, practical way of continuing to support and show love. It may help to counterbalance the feelings of anxiety, helplessness and guilt often experienced when a loved one goes into care. Relatives have also been surprised and pleased to hear stories thought long forgotten which residents have told to volunteers, and have then offered more details and suggestions.

9. CONCLUDING THOUGHTS

Sound is all around us, a basic part of the lived environment, often absorbed without thought, and we can't normally stop hearing unless we put our fingers in our ears. In listening, we actively and consciously decode and make sense of what we hear: it is a choice, perhaps motivated by social and cultural bias and even aspirations.

This gives sound and music a unique role in preserving the key early memories which underpin our sense of who we are. If memory is impaired, parts of the brain involved in processing sound and music may still function well: a simple trigger fires them up to recreate the past with great fidelity, as if we were reliving the moment of very first hearing. In later life we may choose music to express personality, status, politics, sense of beauty and much else, but the soundscape - background noise - of early times is deeply imprinted, and perhaps even longer-lasting in importance.

Capturing this in a Music Mirror could be a vital lifeline for any one of us.

REFERENCES


ABOUT THE AUTHOR

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