Let the Music Speak for Us

Padraic Garrett

Service Manager for Arts, Disability and Dementia with Jewish Care in London.

I’ve been involved in Music for Life for over 11 years and I was the Dementia Practice Development Worker on the research project described in While the Music Lasts. Jewish Care has been very fortunate to have worked with Linda Rose on Music for Life projects for over twenty years. We are delighted to join with The Wigmore Hall as their lead care and development partner on Music for Life.

We all have tendency to compartmentalise and categorise. Dementia and people living with dementia tends to be boxed into one such compartment. This compartment of life is something, we are all aware, could be one to which we may one day belong, but most of us prefer not to dwell on this possibility. Most of us do not want to think about what it will be like to live with dementia and so it is a compartment of our lives, assigned to the future, that we hope we will never visit or experience. However, there are more than 44 million people living with dementia worldwide.

It is not surprising that we find it hard to consider what it would be like to live with dementia. Dementia is a range of conditions that attack the brain and result in the loss of vitally important brain functions. It is degenerative and so over time the impact worsens. The most common issues people face with dementia are:

- Loss of memory
- Problems with thinking and planning
- Difficulties with language
- Failure to recognise people and objects
- A change of personality
If we allow ourselves to think about it, we ask ourselves what it would be like to live with this condition. How would I cope? Would I be miserable? Would I know who I am any longer? Would my life still be worth living? Will I be lonely? These questions can be hard to entertain so we tend to put them aside and to leave dementia and people living with dementia in their compartment.

The majority of the people living with dementia who take part in Music for Life projects in Jewish Care are residents in care homes. They are usually over 80 years old (and over 90) and they are usually significantly physically and mentally frail. Dementia is usually the most significant factor that has led to their admission to the care home. However, they are often also living with other disabilities too, such as visual impairment, loss of hearing, and mobility issues. Daily living presents them with many challenges. Every resident in the care home is an individual with a unique life history, but they now find themselves living in this communal environment with perhaps 15, 30 or 40 other residents. Very few, if any have lived in a residential community before.

We all strive for our care homes to be warm, friendly and happy places to live. Our staff teams receive training on person centred approaches that put the individual resident at the heart of life in the home. Our aim is to offer residents opportunities to continue to live meaningful lives and for their families and friends to stay connected with them.

However, we have a long history of institutionalisation in care homes. In the past, routines, rosters and the need to run well organised and efficient regimes of care tended to take priority over the choice and control of the individual resident. Legislation and stringent standards for care home inspections continue to put pressure on the homes’ management and staff to run the homes according the regulations. The financial costs of care often means that the hours available to care staff is limited. Many would argue that they need higher ratios of staff to residents if they are to truly succeed in their aspiration and commitment to deliver person centred care.
Care homes work best when staff and residents form close bonds and where genuine affection is built between them. In London there is great cultural diversity in our care homes’ staff teams with staff from all over the world. When I talk to staff, they often express the privilege they experience to be working in care environments with responsibilities for older people. They have often lived through the experience of not being with their own grandparents and parents, in their homelands, when they were unwell or towards the ends of their lives. I often hear them say that the people in the homes have become their new grandparents and they have a genuine desire to give them the best care possible. It is an emotionally demanding job to be a professional carer to people living with dementia. In order to do this job you need to be able to reflect on each individual resident, to get to know them as a person and to understand the challenges that dementia and other disabilities make on the individuals. It is also very physically demanding and at the end of each working day there can be a sense of physical and emotional tiredness. We have a duty to meet the emotional support needs of care staff working in our homes and to find ways to help them to process and reflect on their daily work encounters with the residents. It is a complex task and we need a variety of ways to do this to meet the varied and diverse needs and styles of individual staff members.

It is precisely because of the complex nature of care homes that, in Jewish Care, we have a policy of involving creative arts, such as Music for Life, in the day to day lives in the homes. There is a strong wish on behalf of everybody working in the homes to deliver person centred approaches to residents to empower them to live fulfilling lives. However, we are very conscious of the constraints we face including limitations on time and institutionalisation. We are also conscious that we need to develop more robust staff support structures that equip staff to engage in reflective practice and to grow in emotional wisdom.

Music for Life has been an inspirational project for Jewish Care. Twenty years ago we wanted to develop a project to engage people living with dementia. We found that it does this powerfully but it also provides great opportunities for staff development. In this project staff and residents and
musicians are equal participants. Staff have opportunities to reflect on their experiences and to evaluate how communication came about in sessions. It is a genuine and powerful opportunity for staff to develop not only dementia skills but more importantly reflective practice and emotional wisdom.

Like many staff who have been involved in Music for Life, it has helped me to grow in my reflection on dementia. My starting point about dementia, should it become part of my own life’s journey, is no longer so negative. For me, dementia is part of life’s journey. A journey, like every other, that brings the potential for growth and meaning. Through my experiences of Music for Life, the questions I now ask about dementia and me in the future are less negative and about how I could cope with dementia. I am now able to focus more on new possibilities. And so I ask:

What art forms and media of expression will be best suited to me?

How will I continue to enjoy life and what will it be like to live without inhibitions?

What will spark my enjoyment?

How will I express my spirituality?

I hope that I will have opportunities for creative expression when I have dementia because I believe it will be central to my wellbeing.