

# <u>Dancemind - Alzheimer's Project Evaluation Report</u> By Kath Kimber-McTiffen

## **Background and Context**

In 2011, Dancemind ran a year long dance and dementia programme funded by Big Lottery, Awards for All entitled, 'Moving Memories'. This project took place at Thackley Green Specialist Care Centre in Corby (Shaw Health Care), Northamptonshire. The programme was designed to enable those affected by dementia access to a weekly dance class. The programme proved extremely successful culminating with additional dance taster sessions being rolled out across the area in other care settings.

Towards the end of 2012 a further opportunity arose for Dancemind to apply for funding to support a similar project through The Big Lottery, Awards for All. This time, Dancemind decided to design a programme of dance in partnership with The Alzheimers Society who identified Eleanore House in Northampton, which is used for their day centre services, as an appropriate venue to target service users living in the community with dementia. People with dementia attend the day centre, most commonly referred through social services, once a week which provides time for social and recreational activities, giving carers some much needed respite.

The programme of dance and movement is designed to improve the overall sense of well-being of those affected by dementia. Other health benefits include improved levels of co-ordination and physical fitness as well as aiding memory loss.

Statistics published on The Alzheimer's Society website state that there are currently 800,000 people in the UK alone with dementia, including 17,000 younger people (under 65), and it is anticipated that by 2021 this figure will top 1,000,000 with an estimated healthcare cost to the UK topping £23 billion. 60,000 deaths are attributed to dementia each year, with two thirds of people with dementia living in the community and one third living in care homes. (1)

'Increasing recognition of the potential benefits of a non-verbal, body-oriented focus as people's cognitive abilities deteriorate, positions dance projects potentially in the forefront of the field of dementia care, complementing, and perhaps in future, even replacing pharmacological interventions as they become increasingly expensive in these cash-strapped times.' (2)

The effectiveness of dance and movement is starting to become more widely recognised and a number of dance artists and arts and health organisations are undertaking studies in order to provide more robust evidence of the impact of their work. Daphne Cushnie, Independent Dance Artist is currently working on the project Dancing Recall: Making Connections which aims to 'bring a clinical perspective to the practice of community dance'. Daphne Cushnie states that, 'dance, the lyrical, non-didactic flow of movement, can still engage the latent muscle memory that survives the onset of the disorder' (3)

Dancemind formed a partnership with The Alzheimer's Society in Northampton who identified a group of service users who would benefit from the project. The day centre currently has no financial support to be able to run additional activities, therefore, all activities are run by staff or volunteers. Consequently, there was a strong need for an



external activity such as dance to take place at the day centre. Running a year-long project would allow a significant amount of time to measure the overall impact and sense of well-being of an established group who prior to this project had not had access to anything like this.

Following a successful funding bid to Awards for All, the project, entitled '*Move Through Time*', launched in September 2013 at Eleonore House in Northampton for the duration of 36 weeks.



## **Project Aims**

The aim of the project was to provide a weekly dance, movement and singing session for those living with dementia in Northampton in order to increase their sense of well-being by getting everyone active and bringing the community together to take part in a shared group experience.

'The term dementia describes a set of symptoms including, memory loss, mood changes and problems with communication and reasoning' (4)

# Structure of Project

The project ran in four 9 week blocks over a period of a year from August 13 to May 14. Weekly dance, movement and singing sessions took place on a Wednesday morning for an hour between 11.20am and 12.20pm. Sessions were delivered by experienced dance and health practitioner, Tina Heeley from Dancemind.

An average of 17 service users took part in the sessions each week alongside 6 to 8 staff and volunteers from The Alzheimers Society.

Service users were those living with dementia who attend the day centre as a form of respite for their carers. The sessions were delivered to the group of service users who were in the younger age category (under 65) and ranging from age 53 to 65, with mild to moderate dementia.



## **Evaluation Methods**

The following methods were used:

- A total of four observation visits over the duration of the project to observe Dancemind delivering the sessions
- Regular feedback and progress meetings with session leader, Tina Heeley from Dancemind
- Discussions and feedback with care staff and volunteers from The Alzheimers Society
- Feedback from service users during and after the sessions
- Photographic evidence taken from the sessions



# **Structure & Content of Weekly Sessions**

The sessions each week were structured in a similar way which encompassed;

- a warm up
- a number of routines set to music using dance and movement sometimes coupled with singing
- use of a range of props
- free improvisation
- a cool down

Dance, movement and singing activity took place in a seated circle and progressed to standing during the session, finishing with free improvisation where participants, if they choose to, danced in and around the centre of the space facilitated by the dance artist.

The sessions always began with Tina greeting each participant individually, engaging with every single person in the room, checking that they are okay, feeling comfortable and reminding them of the options to either sit or stand during the session. Tina brings the attention of the group together by encouraging the group to hold hands,



uncross their legs and take off their shoes, if they are comfortable doing this. This provides a focus and sets an expectation for the session.

Tina uses familiar songs with actions that gradually build throughout the session, allowing participants to explore and increase their range of movement as well as challenge themselves with increasing complexity of sequences. The use of varying props give a focus for the movement tasks, enabling the participants to focus on the prop itself whilst the movement just happens, this takes away any embarrassment that some participants might initially feel about dancing, as well as provide an additional stimulus for movement and often enabling the participants to extend their range of movement further than they could have done without a prop. Props used during the sessions included; shakers, ribbon sticks, polystyrene pipes, claves, scarves, balls, bubbles and a giant elastic band.

Familiar songs included; 'Daisy Daisy', 'I am the Music Man' as well as songs related to the time of year, i.e. '12 Days of Christmas'. Singing is always encouraged alongside the movement especially at the beginning, and some participants are contented just to join in with the singing whilst warming up, whilst others are keen to move and sing together.

The freestyle dance improvisation at the end of the session is an opportunity for participants to interact with each other and dance in any way they wish. It is an opportunity for creativity and self-expression, with the emphasis placed on no right or wrong way to move.

## **Progression of the Project**

Feedback from participants and observations indicated that the sessions were received positively every week, right from the beginning of the project, During week 3 of the project one carer said, 'they love it, watch their faces, Tina's amazing!'.

Tina noted that by week 9 of the project the group, who had been attending regularly, had bonded together and as a result the sessions became calmer. The participants were familiar with the structure of the sessions and therefore had no fear of the unknown, so they felt more comfortable and relaxed. Staff and volunteers contributed to this by being extremely supportive of the project.

By week 29 of the project there was a notable difference in the confidence and focus of the group. The atmosphere in the room was more relaxed and Tina was providing more physical challenges for the group. A marked improvement was noted in the energy levels of the participants and the activities in the session had progressed to standing, rather than seated, for a significant part of the session. It is important to note that Tina always gave an option for the movement to be performed seated if a participant felt that they didn't want to or were unable to stand.

During the final week (week 36) of the project all participants were observed to look comfortable moving both during and in-between set songs and using their improvisatory skills. As the session progressed, the dance gradually became more free and into the centre of the space where people danced and interacted together. There was lots of laughter shared during the interactions, the group were confident enough to lead and let the dancing flow.

A Service User comments, 'We all get on when we all get together, we have a good laugh. It's a challenge getting everything right but it's good.'



Tina comments, 'they are happy in the moment which is really important for those living with dementia'.

# The impact/benefits on Service Users

Participants were categorised in the younger age category (under 65) for those living with dementia and also at different stages in the illness. In some cases, it was very difficult to identify individuals who were service users as their condition was in its very early stages, whilst for others the signs were clearly visible. All service users, however, were able to engage with the sessions in some way, with varied ability.

During one of the sessions observed, one lady who was in a wheelchair, was able to join in with the whole session using her arms, she looked very alert and had a smile on her face throughout the session. One gentleman joined in sporadically with the movement throughout the session as well as singing loudly at the top of his voice for much of the session until he was removed from the session by one of the carers as he was causing irritation to some of the other participants. Another lady who slept through most of the session woke up towards the end and smiled, obviously engaging with what was going on around her. As the project progressed through the weeks this particular service user had deteriorated in her illness, and a carer noted that she now spent most of her time sleeping, however, she felt it was extremely positive that she managed to stay awake for the a whole song at the start of the session.

The different personalities of the service users came across in the sessions with some more outgoing than others. You could feel by the end of each session that the atmosphere had really lifted. Towards the end of the session Tina encourages everyone to improvise with their dancing, and on one occasion everyone danced with scarves to the band Abba. There was lots of fun, laughter and joyous singing clearly evident in the room, and the session finished on a high.

A strong element of the session is when Tina encourages the group to sing along with the songs they are moving too, it's clear that service users are able to remember words to songs and get a lot of enjoyment from this activity. A session observed just before Christmas began with a sing-song complete with actions for the '12 days of Christmas'. The group had already been singing this prior to the session and were keen to help out with remembering the words of the song. At the end of the song there was much clapping and cheering in achieving this, enhancing the relaxed and joyful feeling in the room.

Tina comments on her use of music in the sessions as a way to help trigger memories. During sessions Tina picked up on these memories, facilitating discussions about the artists singing the songs and any stories that accompanied them. Sometimes Tina would mention a dance or another fact about the music that also triggered memories. The discussion is very much part of the whole session, framing the moving and dancing with lively anecdotes related to the music they are listening to.

Tina uses a variety of props in the sessions to engage and offer a focus to the participants. One session, observed in week 9 of the project, included the use of small balls which the participants could squeeze between their legs and hands. It was noticeable that everyone engaged with this activity and it was fun because it was set to lively music and repeated, allowing everyone to get the hang of the sequence.



All participants looked alert, at ease and familiar with the activity, including a lady in a wheelchair who had less mobility than some of the other service users. Participants were relaxed and there was always laughter in the room. Whilst some of the moves were more challenging, it was noted that the overall energy of the group really rose to these challenges, what Tina refers to as a 'mind-body workout'. Tina always gave a choice to perform the movement standing or seated and the option to follow and copy the movement was never compulsory. A service user commented at the end, 'that was brilliant, absolutely brilliant!'

When Tina gave out shakers as a prop during week 9, everyone started to play them in time with the music without any prompting, clearly showing the confidence that she had instilled in the participants. One service user further along in his illness was engaging with the session by tapping in time to the music and moving his leg. Another lady, who was in a wheelchair, arrived late to the session, however, Tina brought her into the session by initially offering her a shaker which she enjoyed shaking until she came naturally into the circle of activity. Tina encouraged participants to get up and move within the circle if they wanted to, many had the confidence to do this dancing with great energy. Another comment noted was, 'she can stay all day as far as I'm concerned' and one service user said, 'I've never felt better!'



In a session later in the project participants worked with a large elastic band that enabled the group to work together and provided a resistance for them to work out their arms and upper body. Other props included 'claves' which had been introduced in a previous session. Tina asked them if they remembered the name of the instrument, which some of the participants did remember. It was lovely to observe participants playing their own rhythms and copying each others rhythms and feeling confident about contributing creatively.

During this particular session comments from service users included; 'that was good' and when Tina responded that they were more confident, the response with a smile was, 'it's only taken about twelve weeks'. There is an obvious rapport and trust that has built up, with the group responding positively to Tina. Following the final session, service users talked very fondly about Tina, one stating, 'I would like to carry on with the session, she's nice (Tina), and everyone gets on with her and she's on the ball. She knows what she's doing and doesn't get cross. I hope she comes back'

As the weeks rolled out, one thing that became evident was that the group generally became more confident as well as having more energy and focus. In particular, they



became more comfortable with free creative movement and improvisation, with Tina encouraging this by allowing the participants to lead and copy each others movements.

## **Staff/Carers Perspective**

A number of staff and volunteers took part in the sessions each week and were able to experience firsthand the impact of the session on the service users.

One staff member noted that 'one service user is a very shy man who doesn't normally engage with the group, however, he has never missed one of Tina's sessions'. She can see that the sessions are having a big impact on this particular service user and that he really enjoys coming. In general she can see that the group became more active and that they love to dance and sing. Another service user doesn't like exercise, however, he loved joining in with Tina's sessions each week and his physical health benefited from participating in the sessions.

One staff member noted to Tina, 'they really do appreciate you coming in' and another staff member commented about the sessions overall, 'It focuses their mind and in the moment they are having fun whilst exercising. As they are having such a good time, they just go with the flow. It's very difficult to measure, but we need to keep the momentum going.'

The day centre manager has noticed a particular impact on the younger members of the group, noticing that over the weeks their inhibitions have disappeared and their confidence has grown. She commented that the participants really looked forward to coming to the day centre to take part in the sessions, 'One service user is up ready and waiting to come every week and really looks forward to coming to Tina's session, it will be interesting to see how she reacts now that the sessions are no longer running'.

One carer who is the husband of one of the participants came and watched one of the sessions and noted that 'there was not this kind of atmosphere in any of the other places that his wife attended' he remarked, 'it just buzzes' and liked the fact that the session was a separate group taking place in an identified space.

The project has also had an impact on staff and volunteers who have been able to take part in the sessions and have been given an opportunity to view the service users in a different light, 'It makes you realise that when you are participating you don't see them as having a disability they are just people enjoying the session'. In addition to this, 'the staff are able to see how much the service users 'lift up' and even in the afternoon they are still buzzing and sometimes don't even want to go home' (5).

## Challenges

The main challenge of the project Tina reports has been 'keeping them motivated and focused for an hour and ensuring that all individual needs are met'. However, this challenge has been met and a highlight of the project for Tina has been seeing very clearly the positive impact that the sessions have had on the group, the fact that the group has sustained good numbers consistently and that she feels she has been accepted into their community.



There have also been some other minor challenges along the way, such as some staff or volunteers joking around during the sessions in order to cover up their own embarrassment which in turn encouraged some service users to join in. This could sometimes be distracting but was overcome in time and highlights the importance of training and education for staff in this very specific way of working. On the whole, staff have been extremely supportive of the project and have benefited from taking part.

Another challenge to overcome was when one service user started trying to encourage others in the group not to join in with activities. This was identified as a personality issue, often triggered/exacerbated by the dementia, and staff were extremely supportive in dealing with this.

At the beginning of the project there were around 21 people taking part including staff and volunteers. A group this size is particularly large for this kind of work, however, it was also a positive sign showing the interest and desire to take part in the project. Tina felt that the large numbers made the sessions intense at times and that perhaps she was not able to offer as much individual attention to the service users as she normally would. As the project progressed over the weeks, numbers dropped a little which made the group more manageable and, on a positive note, overall attendance remained consistent.

# Conclusions/Summary - A sense of wellbeing?

This particular group consisted largely of service users whose dementia was mild to moderate. That combined with the group being in the younger age category meant that Tina needed to adjust the sessions to accommodate the higher level of the participants physical ability.

Overwhelming feedback from staff, carers, service users and Tina plus observations indicate that the project achieved its aim of increasing a sense of well-being amongst the participants of the group. Whilst it is extremely difficult to prove any long-term benefits due to the nature of the illness, equally, it is vitally important that those living with dementia have the opportunity to experience positive outcomes when being 'in the moment', which has been achieved during this project. It has also been noted that many service users have looked forward to coming to the sessions and the positive atmosphere from the sessions that took place in the morning continued to spill over into the afternoon.

Becoming more alert to the importance of posture, gesture and non-verbal communication with people who have lost or are losing capability, in relation to activities of daily living, can make a real difference to observed well-being and quality of life (6)

It has been proven that this kind of activity enhances well-being because dance and movement is a form of creative non-verbal communication. It is very important to experience non invasive touch as this helps with bonding, feeling human and being cared for, these sessions have provided this. Older people especially crave physical contact because they often lack human touch as they age due to losing loved ones or intimacy. Dance and movement can often find ways for people to interact together involving non invasive touch and making them feel wanted, needed and even loved.

The sessions have also allowed staff to see the service users differently, from both a physical and emotional perspective, and especially in comparison to the current



activities they participate in, such as quizzes where there are only right and wrong answers. In Tina's sessions the service users learn and experience that dance and movement can never be wrong, it is creative and fun, it is about freedom and just 'being', it is about laughter and sometimes being silly, and this makes them feel confident and happy in that moment.

Staff are also able to enjoy the sessions because they are not leading and they are also getting the physical benefits, therefore, the sessions help to reinforce positive relationships between staff and service users.

To conclude, 'It's good for us, I like it. My favourite thing is the ribbons, I didn't like getting up but I always do and then I like it.' (participating service user)



#### Where Next? / Recommendations

The latest National Institute for Clinical Excellence (NICE) guidelines suggests, 'we should converge social and medical streams of healthcare, listen to what real people have to say about what types of healthcare they find most useful and offer community dance for neurodegenerative conditions as one option.' (7) This is also identified in the government's National Dementia Strategy 2007 in key needs for the population.

It's clear that dance and movement has an increasingly important role to play in dementia care, however currently, The Alzheimers Society do not have a budget for additional activities and therefore this project is not sustainable without funding support. In order to achieve a high quality and sustainable project, investment is needed as the cost of running the activity would not be covered by subscriptions from service users. It is also vital that this activity is fully accessible to those on low incomes. Funding support would enable the activity to be open and accessible to all rather than select groups who might be more financially secure.

Dancemind will continue to work in partnership with The Alzheimers Society in order to identify funding support so that the sessions can continue to be delivered by Tina. In the longer term, The Alzheimers Society would benefit from a training and mentoring programme to up-skill their staff and volunteers so that they can confidently lead dance and movement sessions, making the long term aim to sustain the project more viable.

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## About Kath Kimber-McTiffen:

Kath is an independent dance artist, arts manager and evaluator. She is a member of the Dancemind Board and has been involved with Dancemind since it's inception as an advisor and supporter of the work.

## **About Dancemind:**

Dancemind aims to promote health and well-being through dance and movement, aspiring to nurture and support people through community based-arts. The work encompasses an exciting programme of classes and workshops, enthusing health and well-being across a diverse range of people at all stages in life. Dancemind supports those in schools, hospitals, retirement villages, residential/care homes and community settings, offering a holistic approach using dance and movement to support emotional, physical and mental well-being. Dancemind specialises in working with older people and those with dementia. www.dancemind.co.uk

#### References:

- 1. The Alzheimer's Society website, January 2014
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