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A brilliant thing...just doing my own little bit

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It’s almost impossible to go to the doctor or open a newspaper without being told that physical exercise is good for us. The World Health Organisation (WHO 2010) says that regular, moderate intensity physical activity can have significant health benefits, such as reducing the risk of cardiovascular disease, diabetes, colon and breast cancer, and depression.

But there is also evidence that exercise can have more specific health benefits for people with dementia, for example by improving quality of life, neurocognitive function and affective symptoms (mood), and that it can possibly influence the rate of cognitive decline (Erikson 2011; Scarpace et al 2011).

This led to a collaboration between the Liverpool-based exercise service Liveability and a European research project called Innovate Dementia to evaluate the role of exercise for people with dementia. Liveability is a NHS nurse-led award winning service which provides instructor-led exercise classes and gym sessions to the over-50s in the south of the city.

In general, Liveability is designed to deliver health messages, increase physical activity and reduce social isolation by offering structured exercise classes followed by opportunities for social interaction between participants. In the dementia collaboration, the key aim was to increase access to Liveability for people living with dementia. Liveability is a NHS nurse-led award winning service which provides instructor-led exercise classes and gym sessions to the over-50s in the south of the city.

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The Liveability service scheduled two specific (30 minute) exercise sessions each week for people living with dementia and their carers for a period of 20 weeks. Following an instructor-led warm-up, sessions comprised a series of activity stations utilising ‘Technogym’ equipment (exercise bike, upper & lower body strengthening apparatus, Powerplate and free weights) with a group warm-down exercise at the end. Music of the participants’ choice was played throughout the sessions and instructors were available to assist when needed.

For the dementia-specific sessions, the everyday Liveability programme was modified as follows:

• Lower numbers in the class (10 people with dementia and up to 10 carers).
• More staff and volunteers to support and instruct the participants (one instructor/volunteer for two participants).
• All gym staff received dementia training to aid understanding and communication.
• Someone from Innovate Dementia attending each session to offer support, education and guidance, helping to maximise involvement by providing advice on type of exercises, general pacing, and the amount of support people needed to use the equipment and follow instructions.

Outcomes
As well as receiving an initial general fitness check (height, weight, blood pressure, BMI and medication review), the participants and their carers were interviewed at the start, mid-term and the end of the programme. Data were collected via questionnaires, focus groups, interviews and specific validated tools of measurement including DEMQOL, DEMQOL-Proxy and the Pool Activity Level.

This was analysed qualitatively and revealed the following core themes around physical and psychological wellbeing:

Enjoyment and recreation
First, it was clear that both people with dementia and their care...
carers enjoyed the sessions. One individual said “I am enjoying just doing the exercises they are giving me and it’s bringing my body back to normal feeling in myself,” while another saw them as something to look forward to: “You’re meeting people in the group and we chat about different things we have done over the weekend as if it’s normal and nothing is said about the loss of memory. All that’s left at the door and it’s fun.”

Attendance was consistent throughout and the group seemed to develop a genuine sense of friendship and camaraderie as a consequence of the Liveability programme. As one attendee living with dementia said, “It must be a good group because everyone who starts coming, they stay and just want to come back.”

Carers gave the same positive responses in the evaluation, one describing the sessions as a “brilliant idea” which she saw as going beyond physical fitness to be an opportunity for networking with others in similar situations. “We can see a difference too in our crowd. We all talk, we all have conversation. We know what they have got but we ignore that,” she said.

There was also a sense from the data that the Liveability project provided some psychological relief for carers. As the wife of a man living with dementia put it: “I don’t have to worry about [X] because the staff and volunteers look after him and I just do my own little bit and I think this is a brilliant thing just doing my own little bit.”

Improved fitness and cognition
Participants reported feeling fitter, with some members visibly losing weight. One person with dementia talked about the impact on memory, clearly feeling right at home in the sessions: “I felt I was in my comfort zone, that’s the one important thing about it and then it was moving on each time I went it got better and better and better. All the instruments that I had to use brought back the past for me when I was an athlete.”

These remarks were mirrored in the views of a carer who described her husband as “far more relaxed.” She added: “He will doze off and things like that, but the tiredness he is experiencing after the gym is far more positive than if he’s just sat there watching television all the time and so it really does tell.”

Conclusion
So the evidence indicates that the adapted Liveability programme was beneficial for people living with dementia and their carers. One of the questions for us was, would it be able to continue beyond the initial 20-week project? With this in mind the findings from our study were shared with the Liverpool clinical commissioners and they have agreed to fund the programme longer-term so that it will continue now that the project initiated by Innovate Dementia is over.

As a result, the Liveability team have subsequently developed a more flexible model to ensure that people can flow between groups, and that new members can join in. They have also pledged to develop other exercise classes that are inclusive of people living with dementia and their carers.

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