

The Swim England Dementia Friendly Swimming Project









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Background

The Dementia Friendly Swimming Project (DFS) was one of 30 voluntary sector projects to receive a grant by the Department of Health's Innovation, Excellence and Strategic Development Fund in 2014.

There are 850,000 people with dementia (PwD) in the UK, with an estimated cost of £18 billion per year. Around 225,000 people will develop dementia this year and now one in six people over the age of 80 has dementia. Numbers are projected to rise to over one million by 2025 and two million by 2051, with exponential rises in health and social care costs (Alzheimer's Society, 2018).

The DFS approach was developed through collaboration with relevant national agencies including the Alzheimer's Society. The focus has been on achieving a sustainable and comprehensive change in practice that would result in year-on-year increases in the numbers of PwD regularly using swimming facilities.



The Project

The project aimed to make pools attractive to people with dementia by evaluating facility suitability, training staff, development of partnerships and marketing materials to drive recruitment, and the creation of appropriate aquatic exercise opportunities. Below is an overview of the key findings of the project:

- Participants and carers feel that the programme is helping their wellbeing, has increased their confidence and helped them make friends.
- Pool operators believe that the project has brought in new types of customers and that the environmental changes have improved the service for people with a range of health conditions.
- Leisure staff feel more comfortable and are providing a better service for people with dementia and other conditions across the leisure centre.
- Leisure services have developed wider and more diverse partnerships and believe that this has given them better insight to inform future commissioning priorities and helped raise their profile within Public Health and Social Care.
- A number of delivery models have been developed and tested, such as integrated health condition sessions and inclusive sessions.

 New and stronger partnerships have been forged as a result of the programme, for example with local dementia service providers.

DFS started with two pilot areas in November 2015, with a primary aim of learning how best to tailor the aquatic experience for participants and their carers. There were no off-the-shelf training or support packages for practitioners in the field, so it was essential to maximise learning though focusing on extensive appraisal and feedback as the project progressed.

The project included the following components:

- Appraisal of the facility itself and identifying environmental changes to make sure it was suitable and accessible for PwD.
- Training for staff to improve their understanding of dementia and how to provide support.
- Development of partnerships to drive recruitment.
- Development of persuasive marketing information describing the benefits of swimming to PwD and their carers in motivating language.
- Creation of supportive, enjoyable and safe swimming and aquatic exercise experiences.

Development of the project

A series of resources was designed and created to support the development of the project and placed on the website. Since the project began the website has been visited by 7,814 unique users with a total of 9,879 visits and 25,969 page views.

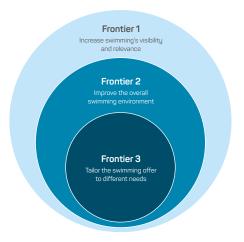
From the start, flexibility was built into the guidance and resources so that new schemes had the freedom to tailor their offer to meet local needs and conditions. A multi-method, action-research approach was designed and implemented. Because of the absence of directives from previous research, Swim England sought to maximise learning as the project progressed, and to feed this learning into subsequent stages of development.

Regular collection of qualitative and quantitative data throughout each stage meant that it was possible to build up comprehensive guidance and a support system for existing and new DFS schemes as the project progressed. Monthly tracker data was centrally held and provided a constantly updated picture of the adoption and usage of DFS services and also advised Swim England's profile of participants.

Key strategies built into the project have included:

- The creation and roll out of Understanding
 Dementia in a Leisure Environment training for all
 leisure centre and pool staff within participating
 schemes.
- Development of partnerships with local authorities and charitable organisations such as Alzheimer's Society to help train staff about the needs of PwD and how to attract them to dementia friendly swimming services.
- A tried and tested checklist with accompanying guidelines for enhancement of facilities and services to increase accessibility and dementia friendliness on site.
- Strategies and resources to support project delivery including shared branding, regular group and face-to-face meetings, online case descriptions and lessons learned documentation that encourage sharing of learning.
- Provision of tailored water-based exercise sessions including aqua-fun sessions, relaxation sessions and structured motivational swimming lessons for participants and their carers.

- Modification of existing pool sessions to make them more inclusive.
- Standardised monitoring and evaluation of participant numbers across all pilot pools to enable ongoing analysis of demographics of attendees and their attendance.



The strategies listed above encapsulate Swim England's Three Frontiers Strategic Model for growth in swimming, which is based on behaviour change research and illustrated above. This model shows the need for a whole-pool approach to supporting the customer journey including: appropriate marketing to highlight the relevance and value of swimming, an inclusive environment, knowledgeable and empathetic staff and tailored provision to meet the needs of specific populations. DFS is entirely consistent with this approach to supporting customers to develop a consistent swimming habit and become advocates of regular swimming.

During Year 1, there were only two pilot sites in Manchester and Durham with a strong programme of assessment and feedback to guide learning and development of the project, with a vision to apply these learnings to larger numbers of sites as the DFS project expanded.

In Year 2 (2016), the project was extended to five further areas; Crawley, Nottingham, Bristol, Barking and Dagenham and Tower Hamlets/Hackney. By the end of Year 2, these schemes involved nine leisure providers and pool operators including GLL, Freedom Leisure, Parkwood Leisure and several local authorities and leisure trusts, delivering DFS in a total of 33 pools. By Year 3 (2017), 48 pool operators were involved delivering in a total of 102 pools.

Case Studies

Experience of a person with dementia

Alice was a recreational swimmer until she was a teenager but avoided swimming until she was encouraged to take part in DFS by her Activities Coordinator and brother-in-law. Alice is 88 and lives in a residential care home having had a stroke and developing dementia. Alice has difficulty with her speech, experiences severe pain in one of her legs and has extreme difficulty walking. She is able to use a rollator frame to get around her bedroom and bathroom but any further than this and she is reliant on other people taking her in a wheelchair.

Alice attends the DFS sessions once a week with the Activities Coordinator and other residents of the care home that she lives in. They come to the sessions via either a taxi or a minibus, the costs of which are added to their monthly bills by the care home, and usually stay to enjoy a cup of tea and a chat in the café after the session.

Alice was initially nervous of participating in the DFS sessions because she 'didn't like the hoist' at the pool. Since then, the group has re-located to a pool with walk in ramp access and Alice is able to be assisted into the pool via a poolside wheelchair, which she feels much more comfortable with.

Alice has reported numerous benefits from attending the sessions. She considers herself to be more active, her water confidence has grown and she feels a lot better since she started going. Alice especially enjoys getting out of the care home, socialising with other participants and likes being in the water because it provides a certain amount of pain relief.

In her own words: "I have difficulty walking very much...I have trouble with my right leg, and sometimes I have a pain down the side...walking in the water helps [with the pain]...I don't swim in there. I just walk, with help...I'll just say it does make my leg, the pain in my leg easier...I wouldn't say it lasts forever, but it does last a while after having been in the [water]...until the evening. I would say I would be walking more in the water...My son seems to think the day after that I'm walking better... with the Zimmer frame."

Alice finds the leisure centre a positive place to be. She feels that the facilities make the experience better, specifically the ramped access and 'the changing rooms are good, I cope because of the handles...and I have help'.

Alice is a strong advocate of the DFS sessions and is always trying to encourage other residents of her care home to attend, especially those with mobility problems.

(Feedback from participant Alice, aged 88)





Clifton Leisure Centre, Nottingham

At Clifton Leisure Centre, the swimming group which included PwD and their carers were consulted on signage and additional provisions they felt would improve facilities. The project officer, area manager and duty manager walked through the changing rooms with a group of seven participants.

The group not only identified the need for signs throughout the changing rooms but also provided valuable insights into the placement and types of signs including a combination of pictorial and text signage. They also provided other useful recommendations including the installation of hooks for towels/toiletries near the showers and benches to place equipment/ sports bags so that people didn't have to place and lift possessions from ground level. The consultation process was extremely useful and the leisure centre aims to meet all of the recommendations of the group.

(Nottingham Dementia Friendly Swimming Report 2017)

Experience of a local authority employee

"When this project was introduced, I thought that it seemed very ambitious and made the assumption that PwD want to go swimming. However, although it has been hard work to recruit people, those who have attended have reaped huge benefits. As well as being more relaxed in the pool, it seems to help with frustration and anxiety in daily living.

"It's a very moving experience seeing someone barely able to communicate and unable to stand, laughing, kicking and splashing once they get in the pool. It has generated a culture change and we are just seeing an increasing trend upwards in the number of PwD going swimming."

(Feedback from Health Improvement Manager, Oct 2017)



Key outcomes

The DFS schemes across the country have developed partnerships with a diverse range of public and private organisations and charitable trusts including local branches of Alzheimer's Society, Age UK, Young Onset Dementia Services, housing providers, Adult and Social Care Services, council officials, community health nurses, and local care providers and carer organisations.

As of December 2017, key outcomes for pools as a result of the project included:

- 102 DFS pools created by 48 leisure operators.
- 895 leisure staff trained.
- 64 cascade trainers created.
- It is estimated that the project reached a minimum of 1,276 people, 531 dementia participants and a further 745 with mixed conditions who attended dementia only sessions.
- 531 people with dementia attending other activities and events.
- 335 carers participated in project.
- A total of 1,181 Dementia Friends created.

Participants have identified the following benefits in their feedback:

- Improvements in wellbeing, including pain reduction, balance functional capacity and fitness.
- Improvements in psychological and social wellbeing such as improvements in mental health, mood, confidence, ability to concentrate and reduced anxietu.
- Improvements in water confidence, swimming ability and physical activity levels.
- Carers valued the ability to socialise with other carers, share experiences and saw it as a springboard to other social opportunities.



Partner organisations have also experienced additional benefits from participating in the DFS project, many of which were integral to their organisation's mission. The majority felt that the programme had already made a positive impact.

Frequently mentioned partner benefits of participating in the DFS project:

- New and stronger partnerships have been forged as a result of the programme, for example with local dementia service providers.
- The programme has already, and is likely to increase, the investment and resources available to run Dementia Friendly Programmes in each local area.
- A belief among the majority that DFS will increase the likelihood of physical activity interventions being commissioned in the future.
- Increasing the profile and strategic importance of dementia locally.
- Providing a new element of implementation of the local dementia strategy.

- Creating a new workforce of Dementia Friendly trained staff.
- Contributing to removing the stigma and barriers associated with dementia in the local community.
- Improving information sharing and collaborative working between organisations.

A desktop study was conducted using the Model for Estimating the Outcomes and Values in the Economics of Sport (MOVES v2). The model predicted average NHS savings of £51 per participant and a small QALY gain, primarily through the prevention of hip fracture. Prevention of coronary heart disease was also an important contributor to the predicted benefit. This compared to an average operating cost of £36 per participant. The return on investment to the NHS was estimated to be £1.42 per £1 invested, or 42 per cent. If one assumes that carers participated at the same intensity and duration as persons with dementia, and derived the same protective benefits from swimming, the return on investment increases to £2.19 per £1 invested, or 119 per cent.

Learnings

Choosing a model of delivery

From the start of the project, an underpinning principle of DFS was to allow flexibility of delivery at the local level. This is because of the reality of great variation among local authorities in availability and suitability of facilities, administrative systems, and available resources. This freedom has produced a wide array of models of delivery, each presumably chosen as best to meet local needs and constraints.

At the start of the project, exclusivity for PwD was the favoured approach and is still maintained, at least in part, in some schemes such as Manchester. However, integration is becoming more favoured, particularly where sessions are opened up to other groups that may include participants with other mental challenges or health needs. This makes economic sense and also fits with a general movement to try to engage people with dementia into more diverse groups of adults and closer to mainstream provision.

At this point, it is not possible to identify an ideal model of delivery. There is no financial evidence on the cost effectiveness of specific approaches. Given that the Swim England Dementia Friendly Swimming Report (Dec 2017) has established that many DFS participants have low confidence and limited recent swimming experience, it seems that dedicated starter sessions are very important. DFS resources provide guidance and scheme reports as exemplars of approaches for new schemes to consider. Scheme coordinators must choose the most appropriate starting model for their local conditions and needs. However, over the last two years of the project, conversations at coordinator meetings have provided greater support for moving towards a more scaled up and inclusive model of delivery.

Multiple activity choices not just for PwD but for people with other health conditions that are held at specific times of the week (usually late mornings or early



afternoons) seems to be the "all singing and dancing" model of delivery. This model is gaining support but may only be appropriate for larger leisure centres that include a swimming facility. It has the potential to gain from joint publicity and stronger recruitment which in turn would enhance chances of sustainability. It is clear that DFS has played a vital role in moving providers to this point in their thinking and provision.

Economic considerations

The current economic climate means that leisure and swimming services are facing reductions in financial support from local authorities. Leisure contracts can be awarded based on the largest potential financial gains and wider outcomes may be secondary. Although leisure operators may have a clear mission to support the health and welfare of the local community, this is becoming increasingly difficult to achieve as they are challenged with the need to create income.



Starting any new scheme is resource demanding. Schemes have estimated that four to six months are required to prepare venues and establish sufficient participants to start a viable programme. Overall the larger schemes have reported total costs for setting up and delivering DFS in the region of £50,000. The largest item has been employment of a scheme coordinator (50-60 per cent) which has been funded through Department of Health funding. This has been needed to manage monitoring and evaluation of the research aspects of the programme, providing reports, attending Swim England meetings, setting up advisory groups, and most of all for building recruitment through outreach and partnership working.

Looking forwards, some of the time-consuming elements will be removed once Swim England's engagement and the research element are reduced or removed. However, it is difficult to see how schemes will achieve successful starts without the drive and time of a scheme coordinator. The degree to

which these posts will continue to be supported by leisure services and charities remains to be seen. In Lincolnshire, this coordination role has been picked up by the County Sport Partnership (CSP). The CSP would be ideally placed to support other projects across England as they have a good understanding of Sport Development and links with wider local partners.

Demographic profile

Gender: Data (n=212) collected from the first three years of the programme indicates that 53 per cent of PwD were male with the larger schemes showing a fairly even gender distribution.

Age: Of the 212 participants and 145 carers who registered with the Year 1 and 2 schemes, more than 80 per cent were over the age of 65 with 20 per cent under 65. There are two registered participants aged between 35-39 years, both having had long term mental health conditions rather than a dementia



diagnosis and were permitted to join. As might be expected, there was a greater range of ages of carers. Just over half of all carers were over the age of 50 while one in 10 were under 35.

Ethnicity: Around 90 per cent of PwD (n=192) defined themselves as white, although there were some exceptions in areas with a larger BAME population. Similarly 80 per cent of carers (n=87) who engaged with the programme defined themselves as white.

Education: The majority (53 per cent), finished their formal education after secondary school. This is not unusual for this generation who are mainly in their 70s and 80s.

Living arrangements: The majority of respondents (n=133) either lived in residential care or a nursing home (37 per cent) or were living independently, either alone or with someone else (36 per cent). There was diversity among schemes which probably reflected methods and sources of recruitment.

Activity levels and swimming ability

Activity level: At six months, 69 per cent of participants reported they had become more active overall as a result of the programme.

Water confidence: At six months, a small sample showed a trend of improved water confidence in both participants and carers, with the highest levels of confidence coming from carers' responses. Due to the sample size, this information should be regarded as indicative rather than a definitive picture.

Swimming ability: A small sample of participants and carers indicated that the programme had some level of success in improving swimming ability. Around half of the sample responded positively, although again this information should be regarded as indicative rather than a definitive picture.



Health and wellbeing outcomes

Additional qualitative data was collected from:

- Scheme reports from coordinators and/or session leaders who sought feedback from their participants and carers.
- 15 participant and 11 carer end of project interviews.
- Detailed participant case summaries via interviews that addressed whether DFS had helped with physical wellbeing, psychological and social wellbeing, and day-to-day life.

Physical wellbeing: A widely reported benefit came from people who suffered joint pain and swollen feet. Water-based activity alleviated pain and discomfort. Most participants pointed to subtle or greater improvements in their physical fitness as a result of going swimming and several reported that their swimming ability had improved. A significant number of the people attending the sessions also have other health issues including arthritis, joint/mobility problems, heart and lung conditions, asthma and high blood pressure.

Psychological and social wellbeing: The interviews produced most comments about mental health and feeling better as a result of taking part in DFS. Swimming and the opportunity to socialise as part of the programme improved mood (particularly sense of joy and happiness). PwD are often conscious that they are losing cognitive and physical abilities and several participants report that swimming was one area of their lives where they felt that their confidence and ability was actually improving. Some felt that being in the water made them feel more alert and mentally stimulated and able to concentrate better. There are examples of some people who start the programme feeling very anxious and withdrawn and who eventually develop confidence in the water and also in social interactions.

Day-to-day living: Participants did not feel that their ability to independently manage activities of daily living had changed noticeably. Similarly, there were no reported effects on reliance on medication or on healthcare professionals or GPs. There were several



references to swimming making people sleep better from both participants and carers and some comments on improvement in appetite. According to some carers, the person living with dementia was now more sociable and more motivated to join groups beyond the swimming group. These are profound benefits that can be a catalyst to better overall quality of life. Although participant experiences and benefits of DFS will vary, some are quite intense and potentially life changing.

Looking ahead

Swim England remains fully engaged in extending the DFS scheme across the country as part of the planned, national roll out beyond the Department of Health funding period.

Partners believe that the programme has already and will increase the investment and resources available to run dementia friendly programmes in each local area, and that DFS will increase the likelihood of physical activity interventions being commissioned in the future.

Swim England will continue to provide support materials and advice to pools seeking to become dementia friendly and seek to build upon the work undertaken and expand the programme to include people with a wider range of health conditions.

Swim England wants to continue to create cost effective solutions that will maximise the use of the pool to deliver aquatic opportunities. This work will target the least active, and support improvements in health and wellbeing.

Swim England's work will include:

- Work with long-term condition charities to get targeted messaging for people with a range of long-term conditions.
- Expanding the DFS training and environmental check list to ensure it encompasses a range of conditions.
- The roll-out of a new Aquatic Activity for Health
 Qualification to support the development of aquatic
 exercise referral schemes for people with a number
 of conditions including dementia.

- Continuing to work with both third sector and health professional bodies to increase recruitment to pools.
- The creation of materials and technology to provide a range of options such as learn to swim, exercise referral and supported exercise classes.
- Expansion of the DFS brand to ensure it is associated with a trusted and consistent aquatic activity offer for people with long-term conditions.

Swim England will seek to spread the findings of the Dementia Friendly Swimming Report (Dec 2017) alongside all the tools developed more widely through promotion of the website, giving presentations at relevant conferences and delivering a seminar to share the findings.

Swim England has taken on board the findings of DFS, the recommendations of operators and the review of Swim England insight data and has subsequently been in discussions with Sport England about continuation of the project and what is needed to create a sustainable model of delivery.

It is clear from the evaluation that the principle of using the Three Frontiers Strategic Model to create a whole-pool approach to supporting PwD has created a cultural change in pools by:

- Strengthening partnerships to support recruitment.
- Making environmental changes.
- Ensuring staff have a greater understanding of clients' needs.
- Creating sympathetic pool programmes.

The Swim England Health and Wellbeing team would like to thank the following organisations for their support in developing and delivering the Dementia Friendly Swimming Project:

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- Alzheimer's Society
- Professor Ken Fox, Continuum Sport and Leisure,
 Chris Skedgel of the University of East Anglia (evaluation team)
- Dementia Design Consultancy
- All of the project site partners, operators and participants.

For more information about the programme and to read the full Swim England Dementia Friendly Swimming Project Report visit **swimming.org/DementiaFriendly**.



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