

Manchester Public Health Development Service
Manchester Mental Health and Social Care Trust

Manchester Supporting Health Dementia Programme

Improving the Physical Health of People with Dementia and their Carers

Progress Report

Status of this Report

This is an interim report on the progress of the Programme pending an independent evaluation report by The University of Manchester in November 2010. It is written by those delivering and managing the Programme. It is an account of progress within the first nine months of the Programme, including the operation of the health check service in its first five months.

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Report Summary

1. The Supporting Health Dementia Programme is a two year pilot (to March 2011) to demonstrate how best to engage people with dementia and their carers in public health initiatives in Manchester. This report examines early findings from programme development and delivery.
2. The Programme has demonstrated the practical potential for opening up new opportunities for people with dementia and their carers to be able to improve their own health, with support where needed and available. This demonstrates progress towards more equitable access to Manchester's initiatives for public health.
3. The Programme has exceeded its targets for the health check caseload (currently 61 people) in 2010 and demonstrated that there is a high level of demand for this attention to individuals' health.
4. It is too soon to be able to report objectively on the degree of health improvement for individual people although the case studies will provide a subjective view. There is good evidence here though of effective engagement with individuals in learning about improving their health, undertaking health checks, using health improvement services and in participating in healthy activities.
5. The Programme has benefited from intensive work to create a place for itself in the pattern of related provision, avoiding duplicated efforts and aiming for sustainability through integrated practice.
6. The Programme needs to be extended beyond March 2011 to demonstrate measurable health improvement for individuals and a preventative impact on other services, e.g. high levels of hospital admission and bed occupancy.
7. Although there is already evidence of good progress, the Programme needs to be extended beyond March 2011 fully to develop opportunities for health improvement that are more widely used, equally available to all, routinely integrated with other services and sustainable.
8. There is a need to look further to effective engagement with carers in maintaining and improving their own health. This has proved to be a longer term challenge.
9. There is a similar need to look further at engagement with people with dementia and their carers in black and minority ethnic communities.

Introduction

The Supporting Health Dementia Programme is a two year pilot established to show how best to improve the physical health of people with dementia and their carers and to indicate the benefits of doing this.

1. Aims of the Programme

- To deliver and evaluate a two year programme up to April 2011
- To ensure that people with dementia and their carers are appropriately included in strategy development and the delivery of programmes for public health in Manchester
- To develop and deliver a programme of physical health checks for people with a diagnosis of dementia and their carers in the community
- To increase access to opportunities for health improvement for people with dementia and their carers
- To demonstrate how best to increase access for health care and health improvement for people with dementia and their carers in selected population groups known to find this difficult
- To demonstrate the potential sustainability of these developments through their integration with specialist mental health, health improvement, voluntary sector and primary care services

2. The Need for this Programme

Dementia is one of the main causes of disability in later life.

- According to the 2003 World Health Report Global Burden of Disease estimates, dementia contributed 11.2% of all years lived with a disability among people aged 60 and over, more than stroke (9.5%), musculoskeletal (8.9%), cardiovascular disease (5%) and all forms of cancer (2.4%). The prevalence and incidence of dementia increases with age.
- There are an estimated (2007) 4,122 people resident in Manchester with a diagnosis of dementia, representing 8% of the total population aged 65 and over, rising to 22% of the population aged 80 and over. Using national trajectories, it is estimated that by 2026 there will be 5,770 people with dementia in Manchester, rising to 8,244 in 2050
- Those caring for people with dementia are also vulnerable to poor physical and mental health and likely to have restricted access to opportunities for health improvement. A 2008 survey of carers found that 77% believed their own health suffered as a result of their responsibilities and 19% ignored feeling ill "all the time". 65% said their own health problems affected their ability to care. The vulnerability of caring arrangements has significant implications for the health and social care economy as a whole.
- People who experience dementia are vulnerable to poor physical health and are often unlikely to have access to opportunities to participate in activities that will maintain good physical health, for example, appropriate physical activity, improved dietary advice etc. Evidence suggests that activities to improve physical health can have a positive impact on mental functioning and challenging behaviours amongst people with dementia, in addition to reducing symptoms of ill health and age related cognitive decline.
- The Alzheimer's Society note that of the 4,121 people estimated to have dementia in Manchester in 2007, only 1,762 (42.8%) were on GP registers for dementia in 2007-8.

3. The Financial Costs of Dementia

The National Audit Office (2010) estimates the direct costs of dementia to the NHS and social care at £8.2 billion annually.

40% of people admitted to hospital have dementia

40% of the work of community matrons is focussed on people with dementia as a co-morbid condition

At least 50% of long term care residents have dementia.

The Alzheimer's Society (2007) estimate that the average cost per person of dementia care is £25,472 and that the total cost of dementia care in England in 2007 was £14.8 billion, projected to rise to £23.9 billion by 2026.

In this context, the preventative potential of this programme could be of financial significance.

4. Policy Context

□ Public Health Policy

This Programme is designed to prevent future ill health and to reduce inequalities in health in line with current public health policy by ensuring that people with dementia and their carers are included in local provision for public health. Manchester's Adults Health and Wellbeing Partnership Board (25.5.10) has agreed dementia as one of four priority areas for its attention.

□ National Dementia Strategy and Manchester Dementia Strategy

This Programme can contribute to the aims of the National Dementia Strategy through

- directly tackling exclusion and discrimination (Objective 1) particularly in relation to access to medical and health improvement services
- information for people with dementia and their carers (Objective 3)
- access to care support and advice (Objective 4)
- improved community personal support (Objective 7)
- support to carers (Objective 7)
- living well in care homes (Objective 11)
- developing an informed and effective workforce (Objective 13)

See also Manchester Dementia Strategy 2009-12. [Manchester Strategy Link](#)

This Programme has been invited to present its work on the Dementia Information Portal which supports implementation of the national strategy, [Portal Link](#)

People with dementia are one of six priority groups for the Manchester Mental Health and Wellbeing Commissioning Strategy [Commissioning Strategy Link](#)

□ NHS Operating Framework 2009-10 & 2010-11

Identifies dementia as an area for local prioritisation. Department of Health memorandum of 1.4.10 identifies dementia services as an area where service development could deliver future efficiency savings.

5. Origins of the Programme

This pilot programme is an extension of the existing Manchester Supporting Health Programme which works to improve the physical health of people with a diagnosis of severe mental illness, implementing a Choosing Health commissioning framework (Dept Health 2006) and directive to Spearhead PCTs. Operational since 2007, that programme is a partnership between Manchester Public Health Development Service

(MPHDS) and Manchester Mental Health and Social Care Trust (MMHSCT) and is financed through Choosing Health allocation. This programme has been positively evaluated and its funding extended from its original pilot status. For the 2009 progress report, see [2009 report](#) . In the course of its operation, the need for similar work to be delivered for people with dementia became apparent whilst it was also clear that such work would require separate skills, partnerships and applications.

Funding for the Dementia Programme as a two year pilot was subsequently agreed through the “improving health” stream of Improving Health in Manchester (IHIM), the process for allocating Local Development Plan investments from 2007-8. This Programme was established on the same basis as the existing programme, i.e. as a partnership for delivery between MPHDS (part of Manchester Community Health in NHS Manchester, see www.mphds.org) and MMHSCT. The Programme became fully staffed and operational in November 2009 and began to accept referrals for the health check service in February 2010.

Planning Programme Delivery

1. Programme Structure

The Programme has two full time posts, a Public Health Development Advisor in MPHDS whose role is to develop opportunities for people with dementia and their carers to improve and maintain good health, and a senior nurse in MMHSCT who conducts health checks and supports access for individuals to appropriate health and health improvement services. These staff work as a team with their respective line managers (including clinical supervision in MMHSCT) to coordinate the development of the programme as detailed in this report.

The Programme is supported and given expert direction by a steering group that meets monthly (see appendix for membership). The Programme has a delivery plan agreed by the steering group. This is implemented with the collaboration and support of important informal partnerships with organisations, as referred to in this report.

The Programme is overseen by the Mental Wellbeing Group for Manchester which coordinates strategy and investments for public mental health and wellbeing in Manchester.

An independent evaluation has been commissioned from The University of Manchester, School of Nursing, Midwifery and Social Work, by the Consultant in Public Health responsible for public mental health for NHS Manchester.

2. Getting Up and Running

This Programme was established as a pilot of two years’ duration. Given that there were inevitable delays in getting up and running due to staff recruitment, the period of operation during which effectiveness can be demonstrated is very short. The staff team responded very rapidly in making vital links to a broad range of services and service users, both for the effective implementation of this pilot and for the longer term sustainability of this work. This initial liaison work has contributed to shaping the Programme and in generating referrals to it. The main areas for this initial liaison were:

□ **Service Users and Carers**

Discussion and consultation at Dementia Cafes, through voluntary sector organisations (below) and attendance at Carers' week event.

□ **General Practice**

Letters introducing the Programme to all practices.

Visits and discussion about the Programme with nine practices.

Presentation to North Practice Based Commissioning (PBC) and meeting with Central PBC manager. Meeting with South PBC pending.

□ **Independent and Voluntary Sector Organisations**

A letter introducing the Programme sent to wide range of independent and voluntary and community sector (VCS) organisations.

Liaison and working relationships established with The Alzheimer's Society, Age Concern, Manchester Care and Repair, The Manchester Carers' Centre, The Manchester Carer's Forum, Salvation Army, Booth Centre, Care Concepts Care Centre based at Marion Lauder House, Care Homes (Mary and Joseph House, Marianna House, Wellfields Residential Home), organisations for black and minority ethnic communities; SEVA, Indian Senior Citizens, African Caribbean Mental Health Services, Wai Yin, Neesa Well Women Project, Longsight and Moss Side Community Project, Chinese Health Information Centre

□ **Specialist Clinical Services**

Meetings with consultants, specialist nurses and other staff at cardio vascular clinics (some of their patients with dementia may not receive a specialist mental health service).

Links developed with specialist NHS dementia services; psychiatry, community nursing, memory clinics, Admiral Nurses, Young Onset Dementia Service.

Presentation to Community Alcohol Team, Phoenix Assessment Unit (assessment and treatment of older adults with SMI and dementia)

□ **Manchester City Council**

Presentations for Homelessness Division and Multi Agency Homelessness Forum.

Liaison with day services at Minehead and Heathfield Resource Centres (Adults Directorate).

Links developed with the Programme Manager, Valuing Older People (VOP), Manchester Joint Health Unit

□ **Health Improvement Services**

Links established with Community Nutrition Service, Manchester Community Health Trainers, Physical Activity on Referral Service (PARS), Expert Patient Programme, Zest (North Healthy Living Network), Leisure Service's Active Lifestyles, Get Walking Keep Walking, MPHDS; Getting Active Through Exercise (GATE), Stop Smoking Service, Sexual Health Team and Alcohol Advisors

3. The Programme Plan

The team developed a detailed plan in January 2010 for their work in the duration of the pilot. Its main objectives were:

- To delineate the health check service with guidance for appropriate referral, settings for conducting health checks, communications with clinical services, recording systems and so on. All person referred to the service should already have a diagnosis of dementia or be caring for someone who has. The plan projected a rolling caseload of 50 people for health checks and follow up over six months each.
- To improve the awareness of dementia amongst health care professionals.

- To improve awareness about dementia in targeted community organisations.
 - Identifying priority groups of potential service users who may be least likely to engage with dementia services. Those groups identified were
 - those individuals not currently engaged with primary or secondary care services
 - people from black and minority ethnic communities
 - cardio vascular patients with a diagnosis of dementia who are not engaged with mental health services
 - people using services for the homeless
 - newly diagnosed individuals
 - To improve access to opportunities for improving health for people with dementia and their carers.
 - To develop health promoting environments, activities and procedures in specialist mental health (dementia) services.
 - Developing information to support health improvement for people with dementia and their carers.
 - Developing a framework for Programme evaluation
- Copies of the Programme plan are available on request (see contact details below)

The Health Check Service

This service was initially built upon the experience of the existing Programme for people with severe mental ill health. In particular it has adopted use of the Physical Health Check procedure developed by Rethink, the national mental health charity. This tool has been recommended for adoption by Manchester Mental Health and Social Care Trust in a draft policy for physical health of service users. [Rethink PHC](#) (For evidence of the effectiveness of this tool, see, *The Physical Health Check: a tool for mental health workers. M.Phelan et al. Journal of Mental Health 2004; 13(3).*) Some additions have been made to this schedule to ensure it's appropriateness for this population group, e.g. checks for continence, falls risk, pressure sores, swallowing and prompts for dental and opticians check ups.

The main features of the health check service are;

- Providing checks for individuals at clinic sessions in a variety of settings, including the client's home.
- Referral of clients to appropriate medical and health improvement services.
- Following up individuals to monitor progress over a six month period.
- Identifying support needs for health improvement activities by the client

Health Check Results

For detail of sources of referral, demographic profile of service users and health check results during the first months of service delivery, relating to 61 people on the current caseload, *see Appendix 1.*

This data represents an early collation rather than an analysis. It is too early in the course of the health check service to be able to present an analysis which will require a longer period of data collection and detailed discussion, including a medical perspective. Results for each health check area will need to be analysed in the context of the overall health of each individual.

CASE STUDY – A CARER

Mr. M cares for his wife who has a diagnosis of Alzheimer's type dementia. He has found it very difficult coming to terms with the diagnosis, and the related changes in his life which he has experienced, including having to give up work, becoming increasingly socially isolated and having to take on new roles which had been previously been undertaken by his wife, for example shopping and preparing meals, whilst undertaking a caring role for his wife. He currently sees an Admiral Nurse who made the referral to the service.

Mr M was experiencing high levels of stress, and had consequently developed hypertension and weight gain. He had also neglected to attend the dentist and optician. He stated that he was experiencing difficulties with his eyesight as his glasses were no longer appropriate for his needs, but was worried about the cost of replacement.

Discussions around the importance of carers maintaining their own health were undertaken with Mr M, focussing on implications for his wife if he were to become ill. He acknowledged the need to maintain optimum physical health to maximise his caring role, and agreed to engage with the exercise on referral scheme and nutrition service to address his weight and blood pressure problems. The Supporting Health nurse liaised with these services to make a referral and also his GP to advise of the health improvement initiatives he was to undertake, as the GP was treating his hypertension with medication.

A local optician was contacted by the Supporting Health nurse who confirmed that there would be no charge for an eye check, and free glasses could be dispensed if indicated. The Alzheimer's Society sitting service agreed to care for his wife whilst he attended the optician. Therefore an appointment was made for him, and new glasses were arranged for him.

CASE STUDY – A PERSON WITH DEMENTIA

Mrs Y has a diagnosis of vascular dementia. She attends a day centre twice a week, and lives independently in her own home, supported by a home care service.

Arrangements to meet with her at the day centre were made with her. During this initial visit, Mrs Y advised the Supporting Health nurse that her left leg was sore. On examination it was noted to be significantly more swollen than her right leg. She also reported pain in her calf. Following a discussion with her key worker at the day centre to establish that this was not normal for her, an urgent call was made to the GP. He attended the day centre within 30 minutes and agreed that there was cause for concern. He arranged for Mrs Y to be taken to hospital for further assessment. She was successfully treated for a deep vein thrombosis, and returned home as per her preferred choice.

Ongoing Supporting Health checks have since been commenced.

Effectiveness of the Health Check Programme

Study of data returned from health checks to date is insufficient to conclude that individuals' health has improved although these case studies do provide some subjective evidence. The data used in this report derives from a 4-5 month period for the first referrals into a 6 month health check process. Therefore many individuals will have been only given the initial assessment and no follow up as yet.

The service has been able to increase early identification of health problems and support with their management.

The service has begun to make clearer pathways to opportunities for health improvement with the support of a range of public health services not previously engaged in working with people with dementia.

The service will require a longer period of operation to demonstrate;

- Measureable improvements in physical health for individuals
- Improved mental functioning resulting from increase in health improving activity and increased resilience to stress, anxiety, depression and sleeplessness
- Improvements for individuals in mobility and independence
- Improved health for carers and support for caring role
- Targeted interventions for individuals with reduced or inequitable access to services
- A preventative impact on other services, e.g. high levels of hospital admission and bed occupancy.

The service has begun to demonstrate that;

- Helping people to make small changes, e.g. advice on increasing their weight, can have an important impact for general health.
- Health checks identify additional symptoms which are notified to GPs.
- Health checks show indications that they can prevent deterioration in health and cognitive decline. Demonstrating this conclusively will require more detailed and longer term study. Health checks may be more effective in this than in improving health. Their combination with take up of health improving activities will also warrant further study.
- The effectiveness of health checks is enhanced by being delivered by a nurse with high level skills and experience, particularly during initial assessment. Less experienced staff could be deployed in a range of follow up activities to enhance the effectiveness of the service.
- Effective joint working with health visitors and active case managers for people with long term conditions has been demonstrated.
- The effectiveness of this service is enhanced by building a working relationship with its users. People with dementia and their carers have benefitted from the relatively greater amount of time spent on assessment and advice and are seen to be more likely to accept advice. This will be further explored through interviews with service users in the independent evaluation.
- Carers have not often taken up formal referral to the Programme. The apparent reluctance of carers to take up the health check service will warrant further exploration and may be an indication that many will place their caring responsibilities as a higher priority than their own health.

CASE STUDY – A CARE HOME RESIDENT

Mrs S was referred to the home by her consultant psychiatrist who had noted deterioration in her physical health which was causing concern for both the care home staff and her husband.

She has a diagnosis of dementia, but had also been experiencing recurrent urine infections which had resulted in weight loss which was exacerbated by a poor appetite.

Mrs S is currently on dementia treatment, but it has been observed that she is also declining cognitively.

An initial visit was arranged to establish baseline physical observations. Although it was noted that she had steadily lost weight, her baseline observations were within normal limits. She was continuing to attend a day centre three times weekly, and staff at the home reported that she was eating well. Mrs S had not had a dental or eye check for over one year, therefore the staff at the home agreed to make arrangements to facilitate this for her. A further visit was also made to arrange to take a routine full blood count and U&E' blood sample.

On visiting her for the second time, staff reported that she had been seen by the GP 3 days previously as she had a further urine infection, and had been commenced on antibiotics. She was not eating or drinking, very confused, had a temperature of 37.8 and had lost 6kg since the previous visit. She was no longer able to attend day care, and staff were concerned.

Discussions with staff took place regarding symptom control and diet and fluid encouragement interventions, but staff remained concerned at Mrs. S's dramatic weight loss.

The GP was contacted and concerns regarding Mrs S were discussed with him. He agreed to prescribe a dietary supplement for her, and would monitor her closely. The Supporting Health Dementia nurse supported the staff to ensure optimum care was given.

The outcome achieved was that Mrs S was successfully treated for her urine infection. She gained the weight that she had lost, her appetite returned, she presented as less confused, and was again able to engage with others which meant that she could return to the day centre.

Arrangements were made with the home to engage with the Public Health Development Advisor within the programme to discuss their health promotion needs for Mrs S.

Promoting Opportunities for Improving Health

The Programme aims to support people with dementia and their carers in having greater access to opportunities to look after and improve their own health with the support of professionals in all sectors. The main approaches to achieving this are;

□ **Improving awareness and understanding of dementia amongst health professionals and health improvement services**

Examples of the Programme's work in this approach are;

- Work with Community Health Trainer Service to facilitate the availability of the service for people with dementia and their carers, e.g. through training for health trainers about working with people with dementia. (N.B. The Supporting Health Programme for people with severe mental ill health has long developed this relationship and has had a health trainer placed within the Programme). The effectiveness of work with people referred to health trainers by this Programme will be evaluated.
- Similarly, work with the Physical Activity Referral Service (PARS) through liaison and training should support an appropriate service for people with dementia and their carers. The PARS Community Engagement officer has established a significant liaison role in this, including direct liaison with Admiral Nurses, Alzheimer's Society and mental health trust (MMHSCT) services.
- Active Case Management Team (South). Initial liaison identified additional needs for the team's support to people with dementia. A training plan and follow up for the team staff has been agreed with support from the Admiral Nurses.

- Similarly, liaison with staff from the Phoenix Assessment Unit, MMHSCT and Minehead Resource Centre, Adults Directorate, identified additional needs to support people with dementia and their carers.

□ **Improving awareness and understanding of dementia amongst prioritised groups and services that support them**

Examples of the Programme's work in this approach are;

Six dementia awareness courses were delivered between Jan. to June 2010, all of which have been positively evaluated;

- Dementia awareness training delivered to Mary and Joseph House which provides for men who have been homeless (19 participants; staff), The Booth Centre for homeless people (17 participants; staff and service users), Manchester Care and Repair, Generation Project (10 participants; staff, volunteers and service users), Manchester Carer's Centre (7 participants; all carers for people with dementia), Neesa Well Women Project (45 participants; service users), Indian Senior Citizens (45 participant; service users). Training has also been arranged for the Asian Carer's Group - Longsight and Moss Side Project (with 40 - 50 carers to attend).
- Following consultation, staff at Mary and Joseph House identified the need for further training about Korsakoff's and Wernicke's syndromes. A half day training session to 17 staff members was arranged to be delivered by the MPHDS Harm Reduction Team with a further half day training for managing challenging behaviour delivered by the Supporting Health Nurse (6 participants, staff). Staff also identified the need for training about motivating individual change and stress management.

□ **Direct engagement of people using the health check service**

Examples of the Programme's work in this approach are;

- Regular review of health improvement needs of health check service users to assess requirements in development of opportunities for health improvement.
- Pilot two fortnightly health improvement sessions, "Health and Wellbeing Afternoon" and "Hearts, Mind and Voices Café" for people with dementia and their carers, one in association with The Alzheimer's Society and the other in association with Admiral Nurses. These pilot sessions have offered dance, health walks, health talks, holistic therapies and health check clinics. Links have been established with PARS, Ramblers' Project (Get Walking, Keep Walking), Active Lifestyles, and Woodhouse Park Lifestyle Centre. The "Hearts Mind and Voices Café" has been used equally by people with dementia and their carers (15 to 20 people). The "Health and Wellbeing Afternoon" has mainly been used by carers (12-15 people).
- Dissemination of health promotion/healthy living information.
- Direct discussion and consultation with people with dementia and their carers about their health needs. This has identified concerns about medication and its side effects, relaxation and better sleep, drinking alcohol, advice on stopping smoking and need for more physical activity.
- An eight week programme of Men's Healthy Living is being delivered for people with dementia and severe mental health problems at Mary and Joseph House following consultation with residents. This included a multi activity physical activity session run by PARS. This group also interested in exploring healthier diet. Some residents have used free swim passes distributed to encourage physical

activity. Evaluation of these sessions has informed aspects of the development of further provision, e.g. recognising problems of concentration (an increase concentration levels/duration has been observed in these sessions), adaptation to literacy levels, effective evaluation methods

- Work is underway to devise a programme of Healthy Living Sessions to be delivered to carers caring for those with dementia at the Carers Centre and similarly, for people with dementia and their carers using the Minehead Resource Centre and the Phoenix Assessment Unit

□ **Promoting awareness of health improvement amongst mental health professionals**

Examples of the Programme's work in development, for delivery September to November 2010, are;

- Work with memory clinics to identify information needs for people with memory problems, including advice on nutrition, physical fitness.
- Develop health promotion sessions for post diagnostic and carers' groups run by Admiral Nurses.
- Develop health promotion training for Admiral Nurses
- Schedule presentation at mental health team (MMHSCT) meetings in North Manchester to discuss availability of health improvement opportunities/resources.
- Develop health promotion training for staff at the Phoenix Assessment Unit

Effectiveness of Developing Opportunities to Improve Health

- Greater awareness and knowledge of dementia has been promoted amongst health professionals and front-line staff, this has given health improvement services such as the Community Health Trainer Service and the Physical Activity on Referral Scheme (PARS) a better understanding of the needs of people with dementia and their carers, enabling these services better to support the referrals made by the Programme (3 referrals have been made to the Community Health Trainer Service, 17 referrals to the Physical Activity on Referral Scheme (PARS) effectiveness of the work to be evaluated).

Recent dementia awareness training delivered to 10 Community Health Trainers also highlighted ways in which the service could work more flexibly to meet the needs of people with dementia. Health Trainers themselves recognised the need to work more intensively with the person with dementia, depending on the stage of progression of dementia and whether the individual could engage in behaviour change, and/or with the family carers. A follow-up session to implement and support these changes and further training has been arranged.

Similarly, evaluations from training delivered to front-line staff at Mary & Joseph House indicated improved awareness and understanding of Korsakoff's syndrome. Staff felt that they had greater knowledge of Korsakoff's, understanding why residents with this type of dementia behave the way that they do. By understanding the dementia and taking a more 'person-centred' approach, staff said that they felt much more confident in supporting the individual.

- Similarly through informal training and discussion, with carers groups amongst Black, Minority and Ethnic Groups, awareness about dementia has been raised.

Feedback from these sessions suggested the stigma attached to dementia; the following comments were noted after the training;

“I didn’t know what dementia was, I thought it was something that happened naturally as we all got older”

“I know and understand, after today what dementia actually is”

“You are right; it is nothing to be ashamed about”

- Health Improvement Pilots

Two fortnightly health improvement sessions for people with dementia and their carers have been piloted; “Health and Wellbeing Afternoon”, in association with the Alzheimer’s Society and “Hearts, Mind & Voices Dementia Cafe” in association with the Admiral Nurse Team.

Both pilots have been well received. Feedback from questionnaires completed by people attending these sessions includes increased confidence, improved concentration, raised self-esteem and increased socialising.

“People are all here for the same reason, feel more motivated, improve social skills, and raise self-esteem”

‘I get a good feeling coming here, I enjoy coming. If you stay at home you feel low and depressed’

Case Study - A person with dementia, A

An account provided by his carer.

A and I started attending the Hearts, Mind and Voices Dementia Cafe at Birch Community Centre in January this year. The dementia café was brought to my attention by our Admiral Nurse. We’d previously visited other Café’s but A seemed to take a liking to this particular Café, this is the only group that A will attend. This I feel, is due to the activities offered such as the dancing, walking and singing. Prior to attending the Café, A did very little physical activity apart from the occasional gardening but I would find that A would soon get bored, causing him to get frustrated and then start to wander.

The benefits for A in participating in a group such as this have been massive. The Circle Dance provides A with structure and helps A to engage and interact with others. It also makes A participate in physical activity without him even realising he is doing it. As A is less mobile and unsteady on his feet, the option of the seated dances still allows A to join in.

By attending the group and through the dance and the repeated moves, I have been able to pick up the extent of A’s deterioration, A has difficulties in sequence; repetition, right and left, clockwise and anti clockwise, this hadn’t been spotted before. Although, A’s memory is deteriorating, he still remembers parts of the dances after the session. I can see that A is trying really hard to concentrate as the dances they are being delivered. I’d say that although there hasn’t been an improvement in memory, A is able to concentrate for longer and sit through the hour as he’s engaged in the activities, the dancing and the music. A loves music, he finds it therapeutic and says it calms him down; this is something I noticed in A after the session too.

There are social benefits too. A feels a sense of belonging in the group and has made new friends. A is much more confident and relaxed (which makes it easier for me). I can see he looks forward to the cafe each week

Case Study – A’s Carer

The Dementia Café has been a huge benefit to us all. As a carer, I’m always on the go and always tired. Whilst A is engaged in the activities, I am able to have some time away, to simply talk to other carers and share my experiences.

Through the various talks that have been offered at the HMV Cafe, I have managed to pick up some useful health information myself and for A. I enjoyed the session around relaxation and breathing. At home, A and I follow the relaxation and breathing technique programme that was given to us at the talk, we try to follow this weekly or whenever we feel we need it. It seems to work, we’re both much more relaxed and calmer afterwards.

The talk around nutrition was particularly useful and has stuck in both mine and A’s mind. A realises why certain foods are better for him than others and we’re regularly having conversations about this.

Development and Impact of the Programme in Manchester Mental Health and Social Care Trust (MMHSCT)

MMHSCT, as the main provider of services for people with dementia, have been enthusiastic partners in this Programme and it is important that this has a wider impact on Trust services so that promoting physical health becomes more widespread and routine for them and so that the work of the Programme becomes more integrated and sustainable. Some of the key developments in the Trust, related to this Programme (and to the Supporting Health Programme for people with severe mental health problems) are;

- The commitment of Trust managers and clinicians to guiding and supporting the programme.
- The development of integrated record keeping through the Care Programme Approach (CPA) and its operating system, Amigos, ensuring that the physical health of service users is less overshadowed by mental health concerns.
- Programme participation in the Trust’s Physical Health Network development group.
- Working to support the role of Assistant Practitioners and Trainee Assistant Practitioners in Trust services, including provision of health promotion training.
- Provision of health promotion training to Trust staff groups, including provision of information during induction of new staff.
- Supporting and influencing the development of a Physical Health Strategy for the Trust.
- Engaging Trust staff and services with the breadth of public health initiatives in Manchester.

Conclusions

1. The Programme has demonstrated many actual and potential benefits for people with dementia and their carers. This Programme will need a longer period of operation to provide conclusive data on what look like very positive results in the pilot period.
2. It has proved more difficult than anticipated to engage carers in taking up the health check service. This will need further research and service development although there are some indications that it may be due to carers prioritising the health of the person they care for over their own.
3. There is a similar need to look further at engagement with people with dementia and their carers in black and minority ethnic communities. Contacts to date indicate the potential benefits of longer term engagement to reduce risk factors (e.g. for vascular dementia) and improve access to opportunities to improve health.
4. The service would operate far more efficiently with dedicated administrative support.
5. There is potential to develop further collaborative working in a number of important sectors, e.g. with GPs and practice nurses, vascular disease and stroke services, hospital inpatients. Initial contacts in such areas have been very positive but have been curtailed by the limits of the Programme's capacity.
6. There is potential for further service benefits by greater integration of the work of assistant practitioners in MMHSCT with the work of this programme.
7. The progress of the pilot shows the importance of scheduling a period of time at the outset of such initiatives to allow for sure progress. This includes staff recruitment, induction and orientation, engagement with relevant services and service users and ensuring that the programme is launched with appropriate support and clear collaboration/integration with the complex range of existing provision.

Recommendations

1. This programme of work has shown a degree of effectiveness over its short operational life. It should be extended beyond March 2011 to demonstrate the potential that is indicated to date.
2. The Programme should be further supported with costs for administrative staff to increase the efficiency of the health check service

Appendix 1

Health Check Data

The following results from a review of case notes provides a profile of the delivery of the health check service between February (when the service opened for referral) and June 2010.

Number of people referred. 61

Number of people assessed, 43 (a further 18 appointments booked)

Number declining service, 2

Number on continuing caseload, 61.

Sources of referral

Self referral	0
GP	6
Admiral Nurse Service	4
Speech and Language Therapy (MMHSCT)	2
Social work (MMHSCT)	1
Consultant psychiatrists (MMHSCT)	7
Adult Social Care (Heathfield Centre)	7
Bridges Day Service (MMHSCT)	2
Age Concern	2
Residential and Care Homes	22
Total 57 (4 referrals source unclear)	

People were seen in a variety of locations appropriate to their circumstances, including Age Concern, day service centres, residential and care homes, homeless people's accommodation and the clients' own home (17)

Demographic Profile

Of 61 people on the current caseload, 38 are men and 23 are women.

58 people have a diagnosis of dementia and 3 are carers

35 people described themselves as white British, 2 as black British, 2 as Irish, 1 as Australian, 1 as French, 1 as Italian and 1 as mixed race. 12 people declined to give an ethnic origin.

The residence of people referred is shown here by postcode

POST CODE	NUMBER
M40	10
M9	3
M19	4
M18	5
M12	23 (largely from 1 care home)
M20	1
M8	3
M22	2
M14	1
M16	1
M11	2
M15	2
M4	1
M13	1
Total	61

The age range was from 50 to 92 years of age.

Psychiatric diagnosis for people referred was;

Alzheimer's disease 17
 Vascular dementia 16
 Korsakoff's syndrome 24
 Small vessel dementia 1

Health Check Results

A sample of ten case notes was reviewed to show the results of health checks.

Of these ten, 4 are women and 6 are men.

1 is a carer and 9 people have a diagnosis of dementia.

Conditions identified by the referrer or from history taken in the initial health check, (some individuals suffering more than one condition) were:

Pre existing conditions

CONDITION	NUMBER
Sleep apnoea	1
Spondylitis	1
Gait & balance problems	2
Mobility problems	2
Hearing impairment	1
Asthma	1
Chronic Obstructive Pulmonary Disease (COPD)	1
Hypertension	1
Angina	1
Stroke (CVA)	2
Peripheral vision impairment	1
Epilepsy	2
Bowel cancer	1
Breast cancer	1
Knee replacement	1
Colostomy	1
Arthritis	1
Depression	2
Recurrent urinary tract infection	2

These further health problems were recorded at the initial health check

SYMPTOMS	NUMBER OF PERSONS
Increased frequency of urination (possible indication of infection)	2
Breathlessness (possible indication of infection)	1
Unexpected weight loss (possible indicator for various illnesses)	2
Chest pain	1

(possible indication of heart problems or infection)	
Increased thirst (possible indication of diabetes)	1
Constipation (potential to worsen symptoms of dementia)	1
Blackouts (possible indicator for various illnesses)	1

Blood pressure checks

Routine blood pressures were taken as part of the initial health check. The blood pressure was taken using a digital monitor with the person in a sitting position. Of the 37 people who agreed to have their BP taken, 2 were referred back to their GP for further discussion.

Substance use:

Of these ten, health checks showed 1 person wishing to reduce smoking (from 30 a day). Two people disclosed they consumed 10 and 14 units of alcohol per week.

Physical Exercise

Following a discussion with the Supporting Health Nurse, 5 people were identified with low levels of physical exercise.

Diet and Nutrition

5 people were identified as having a poor diet.

Enquiries as to routine contact with health services for checks show positive recent contacts. This frequency is thought largely to be due to prompting by the Programme nurse.

Contact with Health Services

CASE	LAST DENTIST APP'T	LAST EYE APP'T	LAST GP APP'T
	9/12	1 year 6/12	1/12
	1/12	1/12	1/12
	4/12	1 year	1/12
	1/12	3/12	2/52
	1 year	3/12	6/12
	3/12	2 years ago	1/12
	1/12	6/12	NK
	NK	2 years ago	NK
	NK	NK	NK
	NK	NK	NK

Of these ten, the following referrals were made to their GP;

REASON	NUMBER
Blood pressure monitoring	1
Prostrate problems	2
Eye infection	1
Raised BP/raised Pulse	1
Jaundiced	1
Lithium levels monitoring	1

Blackouts	1
TOTAL	

Referrals were also made to the following;

AGENCY REFERRED TO	NUMBER REFERRED
Stop Smoking Service	1
Audiology	1
Optician	2
Physical Activity on Referral Service (PARS)	3
Community Nutrition Service	1
Community Health Trainer	1
Dentist	1
Physiotherapist	1
TOTAL	

N.B. Routine prompts are made during health checks to increase take up of dentist and optician check up appointments.

For users of the health check service as a whole, 17 referrals have been made to PARS, 3 to Community Health Trainers, 2 to Stop Smoking Service and 5 to Community Nutrition Service.

Prescribed Medication:

Many reports and studies, for example the NSF for Older People: Medicines and Older People (2001), indicate that older people are vulnerable to the adverse effects of complex medication regimes, commonly known as polypharmacy. As part of her assessment, the Supporting Health Nurse lists the client's prescribed medication. The following information relates to the medication regimes recorded in 41 client records.

- Average: taken across the 41 medication regimes, the average number of medications per client was 6.
- Range: from 11 to 0. One client was prescribed 11 different medications. Three clients were on no medication.
- The total number of individual medications prescribed for the 41 clients was 109.

The medication data needs to be collated before further informed comment is offered.

Reference:

Department of Health (2001) *National Service Framework: Medicines and Older People: Implementing Medicines-Related Aspects of the NSF for Older People*. HMSO, London

Appendix 2

Programme Steering Group Membership

Angela Byrne, Full-time Carer

Susan Ashcroft-Simpson, Admiral Nurse Team Lead, MMHSCT

Catherine Witter, Pharmacist, MMHSCT

Susan Clarke, Manager, Alzheimer's Society

Jane Barcoe, Assistant Chief Executive, Age Concern Manchester

Mary Duncan, Manchester Alliance for Community Care

Philip Hardman, Lead Nurse, Mental Health Services for Older People

Pam Kehoe, Supporting Health Nurse, Dementia, MMHSCT

Tracey Langley, Lead for older people, Manchester Mental Health, JCT, NHS
Manchester

Nat O'Brien, Manchester Carers Forum

Andy Price, Specialist Practitioner, Young Onset Dementia Service

Alpa Raja, Public Health Development Advisor, MPHDS

Dr Joy Ratcliffe, Consultant Psychiatrist, MRI, MMHSCT

Dr Richard Ward, University of Manchester

Catherine Witter, Pharmacist, MMHSCT

Sarah Campbell, Research Associate, University of Manchester

Douglas Inchbold, Public Health Development Manager, MPHDS

Appendix 3

Programme Contact Details

Manchester Public Health Development Service

Alpa Raja. Public Health Development Advisor. 0161 861 2545

alpa.raja@manchester.nhs.uk

Douglas Inchbold. Public Health Development Manager. 0161 861 2543

douglas.inchbold@manchester.nhs.uk

www.mphds.org

www.mhim.org.uk

Manchester Mental Health and Social Care Trust

Pam Kehoe. Supporting Health Programme Nurse. 0161 276 3482

Pam.Kehoe@mhsc.nhs.uk

Phil Hardman. Lead Nurse (Mental Health Services for Older People). 0161 720 2005

Philip.Hardman@manchester.ac.uk

www.mhsc.nhs.uk