Living Well with Dementia in Trafford

Trafford's Commissioning Strategy 2010/2012

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Trafford's Vision

Dementia is an extremely complex, cross-cutting issue so change needs to be locally driven, based on local assessed needs, and take into account what may or may not already be available in a given area. Success in delivering high quality dementia services is dependent on PCTs and Local Authorities agreeing to prioritise this area in their commissioning and working together as partners.

In line with the *'Living Well with Dementia'* National Strategy, and NICE guidelines, NHS Trafford and Trafford Council through their respective Strategic Commissioning Plans and investment programmes are committed to developing further the local dementia support provision to meet the increasing demands in this area over the next 5 years. This work is fully aligned with the Council's plans for transforming local social care services and PCT's integrated care system development agenda for better integration of primary care and secondary care services.

This work has informed the new 'Living Well with Dementia' Joint PCT/Council Commissioning Strategy, which will ensure people with dementia and their carers are enabled to live well through the provision of:

- A diagnosis at the earliest opportunity, including good information and advice about the condition, its effects and support available in Trafford;
- Additional support at appropriate intervals for both the person with dementia and their carer; where pathways to care and support services, whether statutory, voluntary or private sector are clear and interlinked; and
- Care and support which is consistent but flexible and is supplied by trained and competent staff, whether it's provided at home, in the community, in hospital, in residential care or at the end of life.

Foreword

Dementia can affect individuals at any stage of adulthood, it doesn't discriminate against gender, race or disability; it is a complex and progressive condition which has no known cure. Nationally there are approximately 750,000 people with a form of Dementia; over 16,000 of these individuals are under 65. One in fourteen people over 65 and one in six people over 80 have a form of Dementia[1]. Those with Dementia need increasing care as it is a progressive condition which can have a devastating impact on individuals and their families. Using this strategy as a device to develop and transform services, Trafford aims to address the stigma attached to dementia, to improve services for individuals and to offer meaningful support for their families.

Dementia affects more and more people every year. In Trafford in 2010 it was estimated that 2,561 people aged 65 and over had a form of Dementia. By 2013 this number is predicted to increase to approximately 2,697 and by 2030 the number of people with Dementia in Trafford is projected to increase by almost 56% (3,989) from 2010[2].

[1] Source: Alzheimer's Society
[2] Source: POPPI 2010

Trafford recognises the repercussions of Dementia and have taken steps to make the provision of services for this population a priority. To demonstrate their commitment to developing Dementia Services Trafford Council and Trafford Primary Care Trust have invested in numerous initiatives, these include developing a multi-agency Dementia Care Pathway, Memory Clinics, Extra Care Housing, Peer Support Groups for people with Dementia and their families and a Dementia In-Reach Service to improve cognitive stimulation therapy for people with Dementia living in Residential Care, to name a few.

In order to build fit for purpose provision which will deliver high quality and cost effective services to meet increasing demand, strong links have been forged between Trafford Council, Trafford PCT, Health Professionals, the voluntary sector and most importantly people who are affected by Dementia, these links are compounded by this strategy.

This document outlines Trafford's plan to support people with Dementia and their families. It establishes how we will rise to the challenges we face to achieve the goals Trafford have set, and in turn meet the National Dementia Objectives.

Dementia will likely affect all of our lives at some point, directly or indirectly, in these challenging economic times we need to take action to ensure that we are at the forefront of the development of cutting edge, innovative services which ensure Trafford's residents are *Living Well with Dementia*.

Anne Higgins
Corporate Director Communities and Wellbeing

Introduction

Dementia is a disease which is associated with an ongoing decline of the brain and its abilities. These include: thinking, language, memory, understanding, and judgment.

People with dementia may also have problems controlling their emotions or behaving appropriately in social situations. Aspects of their personality may change. Most cases of dementia are caused by damage to the structure of the brain.

Within the general population, diagnostic criteria have been developed in order to improve the accuracy of the clinical diagnosis of dementia. However, it is important to remember that: there is no single diagnostic test; clinical assessments usually last at least 6 months; and the autopsy exam provides the only and final definite diagnostic proof.

Through the consultation programme, both individuals and families requested clarification on what criteria are used by professionals to determine a diagnosis of dementia. These most commonly include using the ICD-10 and DSM (IV) criteria that are summarised below.

ICD-10 criteria

1. Evidence of decline in memory, most evident in the learning of new information. The impairment applies to both verbal and non-verbal material and is sufficient to interfere with everyday function.

2. A decline in other cognitive abilities and daily living skills, characterised by deterioration in judgment and thinking such as planning and organising, and in the general processing of information, to a degree leading to impaired functioning in daily living. These include:
- Language comprehension and expression
- Perception
- Praxis
- Executive function
- Usual daytime activities
- Use of household utensils and equipment

3. Absence of clouding of consciousness/delirium

4. Decline in emotional control, motivation or social behaviour in at least one of the following:
- Emotional lability
- Irritability
- Apathy
- Coarsening of social behaviour

5. The duration in changes in memory must be longer than 6 months

DSM (IV) criteria

The development of multiple cognitive deficits such as manifested by impaired memory, long or short-term, can't learn new information or can't recall information previously learned and is distinguished by:

1. One (or more) of the following cognitive disturbances:
- Aphasia (language disturbance)
- Apraxia (impaired ability to carry out motor activities despite intact motor function)
- Agnosia (failure to recognise or identify objects despite intact sensory function)
- Disturbance in executive functioning (i.e., planning, organising, sequencing, abstracting)

The cognitive deficits above each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

2. The decline in mental functioning begins gradually and worsens steadily

3. The cognitive deficits above are not due to any of the following:

■ Other central nervous system conditions that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, normal-pressure hydrocephalus, brain tumour)
■ Systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B-12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)
■ Substance-induced conditions

4. They aren't better explained by another disorder such as Depressive Disorder or Schizophrenia

In terms of the course of the disease, true dementia (as opposed to pseudodementia due to depressive illness, or dementia like symptoms due to thyroid disorder) is at present untreatable and has a progressive course often divided into 3 development stages:

Early Stage:
- Short Term Memory impairment
- Changes in behaviour and mood (irritable, loss of motivation, anxious)
- Loss of daily living skills
- Disorientation (Time / place)
- Reacting much slower
- Language and word finding difficulties

Middle Stage:
- Increased memory (incl.long term) and language difficulties
- Increased disorientation / confusion leads to: Frustration / Anxiety.
- Decreased depth perception / visual abilities
- Wandering, sleep problems, hallucinations/delusions, 'odd' behaviours, apathy.
- Further deterioration in self care skills / incontinence
- Physical problems (e.g., decreased mobility)

Late Stage:
- Walking / Balance problems
- Difficulty recognising familiar faces, objects, sounds, smells
- Loss of ability to speak / write / understand spoken/written language)
- Loss of eating / drinking skills
- Increase in stereotyped behaviour
- Development of epilepsy
- Often require 24 hr care / become bedridden
- Death typically due to pneumonia, congestive heart failure or other acute causes

Different types of dementia have characteristic clinical features, and listed below are some of the common different types of dementia.
- Alzheimer's disease: where small clumps of protein, known as plaques, begin to develop around brain cells and disrupt the normal workings of the brain.
- Vascular dementia, where problems with blood circulation result in parts of the brain not receiving enough blood and oxygen.

- Dementia with Lewy bodies, where abnormal structures, known as Lewy bodies, develop inside the brain.
- Frontotemporal dementia, where two parts of the brain begin to shrink. Unlike other types of dementia, this type dementia usually develops in people who are under 65.

All types of dementia are progressive and the person's ability to remember, reason, understand and communicate gradually declines over time. How quickly this happens depends on the individual. There is some research suggesting a genetic link to dementia. Knowing at an early stage that there are risks of dementia onset will lead to earlier opportunities emerging for preventative services.

Dementia is very common. There are approximately 700,000 people with dementia in the UK and in fact more than 25% of the population either have dementia or know a close friend or relative who has dementia.

Most people with dementia are over 65 years old, but there are at least 15,000 people under 65 who have the illness. Dementia can affect anyone whatever their gender, ethnic group or social background. People with learning disabilities are at particular risk.

Advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. The effect of ageing on people with learning disabilities – including the increased risk of developing dementia – has become an increasingly important issue. About 20 per cent of people with a learning disability have Down's syndrome, and people with Down's syndrome are at particular risk of developing dementia.

Figures from one study (Prasher 1995) suggest that the following percentages of people with Down's syndrome have dementia:

- 30-39 years 2 per cent
- 40-49 years 9.4 per cent
- 50-59 years 36.1 per cent
- 60-69 years 54.5 per cent.

Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. There is no evidence that dementia affects people with learning disabilities differently to how it affects other people. However, the early stages are more likely to be missed or misinterpreted - particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change. As such, it is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored - particularly where the person involved does not use words to communicate.

The prevalence of dementia in people with other forms of learning disability is also about 4 higher than in the general population, and so need recognition.

Similar increases in demand are likely from other smaller younger groups of people developing various dementia or dementia-like conditions requiring consideration such as those Crreuzfeldt-Jacob disease.

Family carers can often be old and frail themselves. The strain of caring for someone with dementia can cause physical or mental health problems for the carer.

National Context

The most recent relevant source of data about dementia in the UK is *Dementia UK: A report into the prevalence and cost of dementia* by the Personal Social Services Research Unit on behalf of the Alzheimer's Society in 2007. As a result of this research, it is currently estimated that there are over 700,000 people with dementia, including 15,000 younger people (under 65), in the UK. It is estimated that by 2025 there will be over 1 million people with dementia. The proportion of people with dementia doubles for every 5 year age band. At the age of 85, 20% of men and 25% of women have dementia and this is the fastest growing age group over the next 20 years.

The financial cost of dementia in England is over £14 billion pounds a year: health and social care services around £3.3 billion; care home costs of £5.2 billion, and informal care costs, borne by families, around £5.8 billion.

The National Audit Office report *Improving services and support for people with dementia*, 2007, notes that there is a significant diagnosis gap with as few as one third of those suffering from dementia ever receiving a formal diagnosis. There is clear consensus that early diagnosis and intervention in dementia is cost effective, but there are considerable barriers to people and carers approaching their GP about suspected dementia, not least through fear of the disease. A survey of GPs found that there is a widely held perception that little can be done and there is a lack of urgency attached to addressing and diagnosing the disease.

The financial cost of dementia in England is greater than stroke, heart disease and cancer combined and the rapid aging of the population means costs will rise and services are likely to become unsustainable without redesign and focused investment.

Our Health, Our Care, Our Say, 2006 is the Government white paper on health and social care published in 2006 which identified the following priorities:

- Better prevention and early intervention services encouraging GPs, PCTs to work more with Local Authorities
- Give patients more choice and a stronger voice
- Address inequalities and improve access to community services
- Support people with long term conditions and their carers

The desired outcomes articulated in the paper include:

- Improved Health and Wellbeing,
- Improved quality of life,
- Making a positive contribution,
- Increased choice and control,
- Freedom from discrimination and harassment,
- Improved Economic Wellbeing,
- Maintaining dignity and respect.
- Improved Leadership, Commissioning and use of resources

"Putting People First" was issued in 2007 and set out the Government's vision at the time for transforming Adult Social Care Services by offering people much greater choice and control over the type of support that meets their needs and how and where they want to receive that support. People will be able to organise individual services that are personal to them, based on the right support, at the right time, in the right place.

The Putting People First Concordat says we need to focus on four areas to make sure services become more personal and to get the right results for people.
First are universal services, the general support and services available to everyone locally such as transport, leisure, education and access to information and advice.

The second area is the support available to assist people who need a little more help, at an early stage, to stay independent for as long as possible (Early Intervention and Prevention Services). These services include help to safely maintain home and garden and help such as Telecare.

The third part of Putting People First is about self directed support. This means individuals being in control of the process and having personal budgets which they use flexibly to organise the right support for them. Systems should be easy to follow and everyone involved should work together with the person at the centre of the plan.

The fourth part of Putting People First is about making sure everyone has the opportunity to be part of a community and experience the opportunities, rights and responsibilities that come from being a citizen.

National Mental Health Strategy (New Horizons) is a new strategy building on the achievement of the 10-year National Service Frameworks for Mental Health and Older People that will promote good mental health and well-being, whilst improving services for people who have mental health problems. It will build on the National Service Framework for mental health - widely acknowledged as the catalyst for a transformation in mental health care over the last ten years - which comes to an end in 2009. The focus is on prevention and maintaining good mental health.

Carers Strategy for the 21st Century sets out the Government's short-term agenda and long-term vision for the future care and support of carers.

Next Steps in implementing Older People's National Service Framework covers the following themes:

- Dignity in Care
- Joined up Care
- Healthy Aging

Interest in the field of dementia has increased significantly over recent years, with a range of publications focusing on the needs of both older people and those with dementia.

In 2005 the Department of Health and the Care Services Improvement Partnership (CSIP) published ***Everybody's Business: Integrated mental health services for older adults: A service development guide*** (CSIP, 2005). This document set out the essentials for a service that works well for older people's mental health in general.

- It addressed memory assessment services to enable the early diagnosis of dementia for all.
- It describes integrated community mental health teams whose role includes the management of people with dementia with complex behavioural and psychological symptoms.
- It recognised that effective services for older people with mental health problems and disabilities would only be achieved through joint working and efficient partnerships.
- Success would require staff and professionals in services to be prepared to do things differently.

The **National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE)** published a **joint clinical guideline on the management of dementia** in 2006 (NICE/SCIE, 2006). Key recommendations included:

- Integrated working across all agencies;
- Provision of memory assessment services as a point of referral for diagnosis of dementia;
- Assessment, support and treatment (where needed) for carers;
- Assessment and treatment of non-cognitive symptoms and behaviour that challenges;
- Dementia care training for all staff working with older people; and improvement of care for people with dementia in general hospitals.

Several reports have also highlighted inadequacies in all services for people with dementia.

Raising the Standard **(Royal College of Psychiatrists, 2006**) concluded that there needs to be better co-ordination between agencies. Older people with mental health problems and learning disabilities may have complex needs and may need to draw on expertise from a number of areas including specialist mental health, older peoples' mental health, generic dementia, and learning disability services. It also advocated the development of joint working practices between learning disability, mental health and

older people's services. In some places this may involve the formation of joint teams and working practices.

The **National Audit Office** in their report (NAO, 2007) was critical of the quality of care received by people with dementia and their families. It found that the size and availability of specialist community mental health teams was extremely variable and that the confidence of GPs in spotting the symptoms of dementia was poor and lower than it had been in 2000. They also commented on deficiencies in carer support. The report concluded that, overall, services are not currently delivering value for money to taxpayers or people with dementia and their families; that too few people are being diagnosed or being diagnosed early enough, and that early intervention is needed to improve quality of life; and, finally, that services in the community, care homes and at the end of life are not delivering consistently or cost-effectively against the objective of supporting people to live independently as long as possible in the place of their choosing.

The NAO advocated a 'spend to save' approach, with upfront investment in services for early diagnosis and intervention and improved specialist services, community services and in general hospitals, resulting in long-term cost savings from prevention of transition into care homes and decreased length of hospital stay.

The Commission for Social Care Inspection reported on people's experiences of living in a care home in their report ***See Me, Not Just The Dementia*** **(CSCI, 2008**). Amongst its findings, the study demonstrated that the quality of staff communication with people with dementia has a major impact on their quality of life. This confirms the importance of a positive communication style with people with more advanced dementia. The findings support the importance of well-trained and supported staff working in homes committed to person-centred care. Care home managers need to provide leadership, home ethos, staff support and training to ensure excellent personalised care; and to develop ways of assessing the well-being of the people with dementia they are caring for. Local councils and Primary Care Trusts need to procure services at a price that allow for the one-to-one communication and trained staff essential to people's quality of life and well-being.

As a result of these documents and the increase in interest in dementia, the Government has continued to make dementia a priority and consulted widely on a **National Dementia Strategy** (DH, 2008) prior to the publication of the final version ***Living well with dementia: A National Dementia Strategy*** **(DH, 2009)**.

The National Dementia Strategy aims to transform the quality of dementia care. It sets out initiatives designed to make the lives of people with dementia, their carers and families better and more fulfilled. The recommendations are focused on three key themes of: Raising awareness and understanding and removal of the stigma that surrounds it; early diagnosis and support/intervention; and improving the quality of care for people with dementia by developing a range of services for people with dementia and their carers which fully meets their changing needs over time. The strategy, which has 17 objectives, will form a five year plan relating to all people with dementia,

including young people with dementias and those with accompanying learning disabilities. Its intentions are clear and transformational – to ensure that significant improvements are made to dementia services across the country.

The previous government announced an extra investment of £150 million within baseline budgets to support local services to deliver the National Strategy and more recently the 2010/11 NHS Operating Framework sets the need to consider the further deployment of the 2% identified non-recurrent efficiency savings to support the service transformation agenda related to Dementia services.

This is based on the recognition that getting good dementia care is both a national and local area for local prioritisation, from both a quality as well as efficiency perspective, as the facts speak for themselves:

- The National Audit Office report highlights potential for the NHS to identify savings and points to efficiency savings of at least £284m per year
- There numbers of people with dementia are likely to double to well more than 1 million people in the next 30 years in England alone
- The direct costs of dementia to the NHS and social care are in the region of £8.2bn annually, with the current cost to the NHS alone estimated at £1.3bn
- 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 residents in care have dementia

The NHS Confederation published Acute Awareness: Improving Hospital Care for People with Dementia in April, noting that recent Government policy reflected a growing awareness of the importance of dementia care a sat a time when cost savings are being keenly sought alongside service improvements, this area could also lead to significant savings. The report noted that two-thirds of general and acute hospital beds are used by people over 65, and although not all older people have dementia, the number with the condition is substantial. Taking into account the high number of people with dementia who use hospital services and the fact that this number is increasing rapidly, it makes sense for hospitals to rethink the way they provide services. Key areas to deliver high-quality care were noted to include: early and better identification of dementia in general hospitals; more proactive, coordinated care management from admission through to discharge planning; appropriate care planning linking dementia accommodations to other conditions patients usually admitted for ; better dementia awareness training for hospital staff; rigorous antipsychotic drugs needs assessment; better nutrition support including practical assistance to eat at mealtimes; consideration of environmental changes such as social areas, signage and easy-to-read information; reviews of effective discharge arrangements including readmission processes/audits; clear senior and visible physician-clinician leadership to champion at both strategic and operational levels; enhanced liaison psychiatric support for people with mental health problems and dementia; and, active involvement of patients and carers in designing individual care plans and strategic service planning decisions. Through this effort, it is argued that improving efficiency and quality of care for patients with dementia can go hand in hand.

The New Government's revision to the Operating Framework for the NHS in England 2010/11 has been published setting out a number of areas for immediate change, including two critical issues for local prioritisation. One of these is ensuring joint local work by NHS organisations with their partners to implement the National Dementia Strategy. It further notes that people with dementia and their families need information that helps them understand their local services, and the level of quality and outcomes that they can expect. Trafford PCT and its partners, principally at Trafford Council, should publish how they are implementing the National Dementia Strategy to increase local accountability for prioritisation. PCTs are not subject to requirements on how or what they publish, and neither will there be any additional national performance requirements.

There are a number of policy drivers which have influenced this strategy.
These include:

- National Assistance Act 1948
- Chronically Sick and Disabled Persons Act 1970
- NHS and Community Care Act 1995
- Disability Discrimination Act 1995
- Equal Opportunities Act 1995
- Human Rights Act 1998
- Data Protection Act 1998
- Carers Act 2004
- Health and Social Care Act 2008

Local Context

NHS Trafford through its Commissioning Strategic Plan investment programme remains committed to developing further its local dementia support provision to meet then increasing demands in this area over the next 5 years. Trafford's Dementia Strategy has been developed in partnership with Trafford Council, Trafford PCT, Age Concern Trafford, clinicians, care providers and voluntary sector providers, and strongly influenced by individual and group consultations with people with dementia and their carers. The action plan co-produced for dementia has involved wide ranging and independently facilitated workshops led by Age Concern with local stakeholders including service users, families, carers, service providers and commissioners. Some of the key action areas identified will include the following identified Priorities for Action (mapped against National Dementia Strategy)

- Consistency across providers and common practice approaches across service providers
- Enhanced service coordination
- Better service information
- Overcoming gaps - Needs assessment, Improve community personal support services for people living at home, Memory clinics, Improve intermediate care for people with dementia, Crisis / out-of-hours, Improve end of life care
- Shifting resources from reactive to prevention services
- Public education / Tackling stigma and effective links with national and regional support for local services to help them develop

These themes have been developed through an examination of our local context, recognising that the situation in Trafford strongly mirrors that seen nationally. The 65 plus age group is predicted to increase from the current 34,500 to 37,400 (8.4% increase) by 2015 and then to 42,200 (22.3% increase) by 2025.

The 85 plus age group, in comparison, is set to rise from 4,900 to 5,500 by 2015 (14.8% increase) and then to 7,500 by 2025, a 53.1% increase.

By applying national prevalence rates to the local population, the Projecting Older People Information System (POPPI) estimates that there are approximately 2,470 people with dementia in Trafford. It is estimated that this will rise to 3,350 by 2025, a rise of 35%. Coupled with this, the Projecting Adult Needs and Service Information System (PANSI) estimates that there are 52 people under the age of 65 in Trafford with early onset dementia. This is set to rise to 61 by 2025. Although the increase, 9, is relatively small this represents a rise of over 17%.

With regard to the diagnosis gap in Trafford, in March 2009 there were 911 people currently registered with a Trafford GP with a diagnosis of dementia, around 36% of the expected prevalence. These figures would seem to indicate that Trafford reflects the national situation, in that there are currently high numbers of people with dementia with unmet needs.

In meeting government expectations and the recommendations of the National Audit Office in addressing these needs we must begin by getting a more detailed picture of

the situation in Trafford than that we currently have. In this way we can continue to design services in the way people want which will provide cost effective earlier interventions, improve the quality of life of those suffering from dementia and their families, and meet the challenges of increasing demands caused by demographic change over the coming years. The implementation of the Integrated Care System approach and the Mental Health Project Group will enable a clearer integration of primary care and acute/specialist services through the proactive identification, screening and flagging shared register system mechanisms.

The strategy interlinks with:

- **Commissioning Strategies –** There are Trafford Council's Adult Social Care Commissioning Strategies for Learning Disability, Physical Disability and Sensory Needs, Older People, Carers and Mental Health which provide information about what people need and how we plan to provide services that meet those needs. This Strategy links directly to those Strategies as any individual citizen may develop dementia.

- **Adult Social Care Service Plan 2009-12 -** This three year plan outlines Trafford Council's Adult Social Care intentions for the provision of care, planning and partnership working across all service user groups.

- **Adult Protection and Safeguarding Policy and Procedures -** describes how Trafford Council's and our partners protect vulnerable adults from abuse or risk of abuse, and where the responsibility lies for reporting and investigating allegations of abuse.

The strategy relates to all adults who have dementia and live in Trafford, and as such is not solely limited to older people.

The strategy is not about, and does not include, specific policies and procedures in relation to how services should be operated. However all commissioned services are subject to quality standard checks through contractual, and service level agreements. Services for children (under 18 years old) are not addressed in this Strategy.

Trafford Council is committed to the development of how Adult Social Services are delivered locally, in line with Putting People First. The change is being led by the Putting People First Steering Group, with links with to the Citizen Reference Board. The broader Transformation intentions are to;

- Support the development of the market, to offer a wide range of quality services.
- Provide comprehensive and accessible Information and Advice.
- Involve Citizens of Trafford in all aspects of service development.
- Provide effective support services to enable people to make full use of their personal budgets, including Support Brokerage, help with recruitment and finances.

Locally, a Dementia Steering Group had already been established and a draft joint Dementia action plan prepared addressing various initiatives such as:

- Enhancing the understanding in both primary care and general acute hospitals to improve diagnosis, care and treatment of dementia
- Significantly enhanced access memory assessment and treatment services
- Developing the Dementia Advisor services
- Expanding the community-based Dementia day groups
- Providing Peer-support Networks for patients and carers
- Better dementia care training and supporting staff to promote and deliver effective person-centred care
- Expanding the options and role of Extra Care Housing in helping provide a range of respite, intermediate care and longer term care options
- Improving the quality of commissioned care home services and safeguarding arrangements
- Improving end of life care

In 2009/10, we introduced the building blocks of a comprehensive local multi-agency action plan in line with the National Dementia Strategy objectives, including agreeing and/or implementing new investments in:

- Good quality early diagnosis and intervention for all through improved local Memory Clinic and well-trained Older People's CMHT services to enable better detection, support and treatment of dementia and older people's mental health difficulties, including enhanced carer support
- Improved quality of care for people with dementia in general hospitals and extended local intermediate care/specialist care home options to avoid delayed discharges
- Improving public and professional awareness and understanding through individual or group psycho-education and support programmes in non-stigmatising resource centres
- Additional support and information by telephone and through the internet
- Training courses about dementia, services and benefits, and communisation and problem solving/caring with confidence of people with dementia
- Involvement of other family members as well as the primary carer in family meetings, and structured peer-support/learning groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics
- Implementing the revised local Carers Strategy, including additional practical support and a comprehensive range of respite/short-break services and peer support networks to meet the needs of both the carer (in terms of location, flexibility and timeliness) and the person with dementia. This has included agreeing plans and providing additional day care, day- and night-sitting, community personal support services, adult placement and short-term and/or overnight residential care, with provision in the person's own home considered whenever possible
- Support to the planned revised 'End of life' support and palliative care strategy for people in Trafford including those with dementia

Trafford Dementia Strategy – Key Priorities

In April 2010 six key local priorities for action were identified through consultation with people with dementia, their carers and service providers in the statutory and voluntary sectors. Each of these key priorities can positively be mapped against the National Dementia Strategy objectives as follows and so demonstrate a joint local/national perspective on the way forward:

Key Local Priority for Action	National Dementia Strategy Objectives
A consistency of provision and practice approaches across all services	**Objective 8** – *Improved quality of care for people with dementia in care homes* **Objective 11** – *Improved quality of care for people with dementia in general hospitals* **Objective 13** – *An informed and effective workforce for people with dementia* **Objective 14** – *a joint commissioning strategy for dementia* **Objective 15** – *Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers*
Enhanced service co-ordination	**Objective 2** – *good quality early diagnosis, support and intervention for all* **Objective 4** – *Easy access to care, support and advice after diagnosis. Dementia advisers for people with dementia and their carers*
Better service information	**Objective 3** – *Good quality information for people with dementia and their carers*
Overcoming gaps in provision	**Objective 6** – *Improved personal support services for people living at home and their carers* **Objective 9** – *Improved intermediate care for people with dementia* **Objective 12** – *Improved end of life care for people with dementia*
Improving access, prevention and early intervention	**Objective 5** – *develop structured peer support and learning networks* **Objective 7** – *Implement the Carers Strategy* **Objective 10** – *Consider how housing support, housing related services, technology and telecare can help support people with dementia*
Tackling stigma through public education	**Objective 1** – *improving public and professional awareness and understanding of dementia* **Objective 17** – *Effective links with national and regional support for local services to help them develop*

Current Services and Resources

In Trafford, the primary care based QOF registers confirm that the crude prevalence rates for dementia vary from 0.04% at the Seymour Grove Health Centre (Kuna) to 1.30% at the Gloucester House Medical Centre, providing an average prevalence rate of 0.37%. This mirrors almost exactly the national noted average prevalence rate of 0.41%.

Trafford's national ranking demonstrates that the prevalence rate for dementia is 149 out of 152 Primary Care Trusts (PCT's).

Trafford PCT notes that the number of people with dementia is expected to increase by approximately 60% over the next 20 years due to an aging population in the absence of any breakthrough in medical treatment. The associated costs are significantly higher than for all other mental health conditions and the result is predicted to be a doubling of the health care costs for mental health services by 2028.

In Trafford, the local older people's service has faced increasing demands for support from people assessed as needing a structured care programme approach, with 64% of current Older People's Community Mental Health Team clients now classified as having complex needs under the Care Programme Approach (CPA) requiring multi disciplinary planning, care and support.

Also, locally people with learning disabilities now have an improved life expectancy and are more likely to live into old age, despite this still being less than that expected for the general population. However, many people with learning disabilities may experience a higher risk of dementia because of premature ageing and additional support will be required to respond to this challenge.

In line with the *'Living Well with Dementia'* National Strategy, and the NICE guidelines *Dementia: Supporting people with dementia and their carers in health and social care* which emphasise how important it is to consider the needs of carers whether these be family members or paid care workers in dementia care, Trafford PCT through its Commissioning Strategic Plan investment programme is committed to developing further its local dementia support provision over the next 5 years. This work is fully aligned with the Council's plans for transforming local social care services.

The Trafford Mental Health Commissioning Strategic Plan noted 5 Key Agreed Priorities over the 5 year-period (08-13) and has now been reconfirmed following a refresh consultation exercise reconfirmed to extend to 2014. These are:

1. Reducing Physical Health Inequalities for vulnerable people
2. Increased Positive Mental Health Promotion / Resilience programmes (especially self help and support to tackle worklessness/incapacity due to mental health issues)
3. Improving Access (particularly to Psychological Therapies)

4. Enhanced Local Care Pathways / Specialist Teams (especially CAMHS and Older People's MH Teams) and increased specialist community/admission support for people with learning disabilities, eating disorders, and mentally disordered offenders
5. Better Support for Families and Carers – in terms of Information, Breaks and Health Checks (especially targeted at older carers of people with Dementia and Learning Disabilities) and additional Respite/Intermediate/Extra care options

Ensuring better dementia support is therefore fully embedded within PCT's 5 year Commissioning Strategic Plan and has been reconfirmed as a priority this year through the World Class Commissioning Refresh Programme and operational plans with requirements and priorities noted in PCT Operating Framework Plan - 2010/11 as follows:

- Establish effective primary care-based registers of people with dementia, people with learning disabilities and their carers, to enable the introduction of a structured assertive outreach physical and mental health screening programme.

- With regard to the diagnosis gap in Trafford, in March 2009 there were 911 people registered with a Trafford GP with a diagnosis of dementia, around 36% of the expected prevalence. These figures would seem to indicate that Trafford reflects the national situation, in that there are currently high numbers of people with dementia with unmet needs. In meeting government expectations and the recommendations of the National Audit Office in addressing these needs we will begin by getting a more detailed picture of the situation in Trafford than that we currently have. In this way we can continue to design services in the way people want which will provide cost effective earlier interventions, improve the quality of life of those suffering from dementia and their families, and meet the challenges of increasing demands caused by demographic change over the coming years.

- Initiate a 3 year costed development programme to ensure plans are agreed so that people who have dementia:
    - Know where to go for help
    - Know what services they can expect
    - Seek help early for problems with memory
    - Are encouraged to seek help early
    - Get high-quality care and an equal quality of care, wherever they live
    - Are involved in decisions about their care

- Using the Greater Manchester West MH Trust-wide review of CMHTs to systematically review resources within local older people's community teams to ensure the delivery of high quality services matching changes in demand that will occur over time, and begin to make a significant expansion in local services

- Continue to invest in the additional support into specialist general hospital liaison older people's mental health services

- Also, given the fact that people with learning disabilities now have an improved life expectancy and are more likely to live into old age, despite this still being less than that expected for the general population, all clinical service developments will ensure equal access to younger people with learning disabilities, and specifically

Down's Syndrome, experiencing a higher risk of dementia because of premature ageing. This will be included within joint action plans agreed between Greater Manchester West and Cheshire & Wirral Partnership Trusts

- Initiate an Dementia Advisor/Admiral Nursing-Carer Support type service, and consider the introduction of additional Caring with Confidence programmes led by the Trafford Carer's Centre, to enable 'expert carers'

    - Extend the provision of 'Time Out' services and access to additional support services

    - Expand the Assessment/Re-ablement/Respite/ Intermediate/Extra Care Support service options through the Joint Council-led Best Value Mental Health and Residential Home and Day Service development programme. This will begin with supporting the introduction of memory clinics, in-reach/outreach services, a dementia café and gym at the new Partington and Timperley Extra Care Housing developments and 8 Age Concern day service programmes situated across Trafford

Through past investments and support, Trafford Council and Trafford PCT have invested in developing a range of local support services and resources for people with dementia and their families, which are highlighted below:

Older People's Mental Health Team

Greater Manchester West Foundation NHS Trust is a partner organisation with Trafford Council whose remit covers three Primary Care Trusts inclusive of Trafford. The current provision within Trafford is as follows:

- Inpatient Services consists of two wards of which Greenway is specialist in assessing people with dementia. This is a 15-bedded unit within the grounds of Trafford General Hospital.
- Within a community setting the service consists of three generic older peoples teams which are geographically located, they all operate a single point of entry in order to maximise efficiency and ensure appropriate response to referrals.

Currently referrals are received via the service users GP or another Consultant. These teams assist people with dementia and other mental health needs. The team's role is to assess, commission services as required, and to support the person to maintain their quality of life for as long as possible in their own homes.

- The North team are based in Sale and cover an area from Old Trafford, Stretford, Urmston and Flixton to the borders of Partington.
- A Central team which is based in Altrincham covers Partington and Sale,
- The South team which is also based in Altrincham covers Altrincham, Hale, Timperley and Bowdon.

The Memory Assessment and Treatment Service within Trafford is key to the Dementia Strategy with regard to early diagnosis. This service has had significant investment from

the PCT in order to expand the team to facilitate a more efficient response to requests for assessment and diagnosis from local GP's. This will enable the appropriate services and support to be put in place at an earlier time in the life of the person's illness and will ensure that, where applicable, that appropriate anti-dementia drugs are prescribed as early as possible.

In November 2009, a Government commissioned review specifically addressed the management of people with dementia using antipsychotic medication. This review highlighted the increased risks for cerebrovascular events and mortality and acknowledged a general need to reduce inappropriate antipsychotic prescribing in people with dementia. The lead author, Professor Sube Banergee called for a reduction in antipsychotic prescribing of up to 66% over a 36-month period. This began in January 2010 and the first audit was expected to be completed within 6 months and then repeated on an annual basis for at least the next 3 years.

The search for viable alternatives including non-pharmacological interventions and other pharmacological approaches was recognised as paramount to ensure both the effective and consistent management of behavioural symptoms in people with dementia. Within Older peoples Mental Health Services of Trafford we have a small team called the Outreach team, their function is to support a person at home by providing education on how to deal with some of the symptoms of mental illness and dementia to both the carers and the person themselves as well as providing support for Local Authority and independent organisations when they find it difficult to cope.

Older People's Social Work Teams

Social Workers on Older People's Community Teams also accept referrals for clients with dementia. If the client has a diagnosis and has been seen by a Psychiatrist, often their condition is at an early stage and they are not displaying any overt behaviours which cannot be managed by mainstream services.

If this staff group are referred clients who are displaying florid or psychotic symptoms and have not been sent by Psychiatric Services, they will refer back to the GP for referral to a Community Mental Health Team. If they have a condition that is diagnosed but have deteriorated they will check to see if they are known to a psychiatrist and then refer back for re-assessment.

Clients on hospital wards may also have dementia which is being managed by mainstream services. If that is the case, the hospital social work team would keep the case. If their mental health deteriorates, the patient would undergo a consultant to consultant transfer to a psychiatric ward.

Emergency social work referrals can often be about carer breakdown where the spouse or family member is living at home. This may necessitate an emergency placement, however additional Carer Services can often support the Carer to continue to provide quality care at home.

Community Social Work Teams have noted that people with dementia would benefit from accessing and being more integrated with the developing reablement and

intermediate care services and so future service developments must include these services as part of delivering the personalisation agenda in Trafford.

Support Services for People with Dementia and their Carers in Trafford

There are many services that support service users who suffer from dementia and their carers. However, not many exist that could be described as dedicated to the specific needs of those accessing these services. Day Support as well as residential care, home care, reablement and respite can be grouped amongst these.

Over the past year reviews of these services have highlighted that dedicated services to support the needs of people with a dementia and their carers is a fundamental requirement in the future commissioning of services in Trafford.

Day Support

In Trafford there are approximately 14 day support providers. These offer a mixture of day support services ranging from large day centres to small community based groups and a model that offers day support as an adult placement in someone's home. Many of these providers support people with dementia. Other than the service provided by Age Concern Trafford, which is a network of small community based groups situated across the borough none are dedicated to the needs of people with dementia.

NHS Trafford understands Cognitive Stimulation Therapy or CST to be a cost-effective, predominantly brief structured group treatment approach for people with dementia administered by varying health/social staff and professional groups. It builds on previous work relating to structured Reality-orientation and Reminiscence and includes sensory integration therapy elements. This type of approach is clearly one that we support as it encourages consistency, continuity and clear communication, all of which have been validated as important components in any successful dementia support service. There is a long tradition of psychological therapies for people with dementia and we are committed to including this in our service specifications for existing and new services.

NHS Trafford is currently already supporting the cross-cutting contributions from other local organisations with respect to additional PCT funding focussed on Dementia Advisors, Safeguarding/ Mental Capacity Act, Psychiatric Liaison support into General Hospitals and increased support for Carers, and has agreed to increase the Memory Assessment and Treatment Services and Community-based Dementia Units providing day care/support groups for a further 30 people with dementia across Trafford. As a result, there is a joint commitment to ensure NICE-approved treatments and evidence-based interventions such as Cognitive Stimulation Therapy are embedded within our plans.

Residential Care/ Respite

Similar to Day Support many sufferers of dementia are supported within the residential sector. Many homes have registered beds or numbers of beds constituting a unit however homes dedicated to the specific needs of people with dementia are not yet available.

Home Care/ Carers

Probably by-far more people with a dementia live within our local communities and are supported by either carers, home care providers or a mixture of both. The support delivered ensures that individuals remain in their homes for longer and prolong the need for long term care for as long as possible. The promotion of maintaining skills to enable individuals to be as independent as possible is achieved through the assessment and reablement service. These services as well as intermediate care, do not at present support people with a dementia, and this service needs to change.

Families and Carers of People with dementia

Carers are not only vital to the quality of life a person with dementia experiences, but for many people they are the only source of recognition and stability in their life. Experiencing diagnosis of dementia has a huge impact on an individuals and their family life and the sense of unknown can be overwhelming for many. Often the role from Spouse or Child to Carer is a difficult transition as people struggle with both the initial diagnosis and the changing stages of dementia. As noted in the report by the National Audit Office (2007) Improving services and support for people with dementia, a "key issue for unpaid Carers is the loss of their own lives as they knew it". This Strategy works to ensure advice, information and support is available both to the person with dementia and their families.

Trafford Carers Centre reported that they currently have 330 carers of people with dementia on their database. Of which:

- 126 people are aged 18-64 yrs old,
- 58 people are aged 65-74,
- 62 people are aged 75-84,
- 19 people are aged 85+
- Of the total number of Carers listed on the database 6% are from BME groups.

Carers currently have access to services provided by Trafford Carers Centre which is commissioned through Trafford Council. Services include a helpline, a casework service to provide carers assessments and advocacy through a dedicated dementia caseworker, 'time out' budgets to enable flexible respite, counselling service, reflexology and massage, emergency card scheme and information factsheets.

Expanded Older People's Mental Health Teams (including enhanced Memory Assessment and Treatment Services and better support for Depression)

This is a critical area for expansion with most dementia still not diagnosed, or diagnosed late, too late for effective intervention and the prevention of harm. Services of proven effectiveness are not commissioned and people with dementia and their families are not aware of availability of local services. The effect is that people with dementia and their families experience a lower quality of life than they should; this includes recourse to premature or inappropriate use of residential care. In their report on the subject, the House of Commons Committee of Public Accounts cited the following:

- In 2006, only 5 people in 1,000 aged 65-69 had a diagnosis of dementia against an expected prevalence of 13
- Of people aged over 80 years, only 60 of an expected prevalence of 122 in 1,000 had a diagnosis.

In addition to under-diagnosis, there is evidence that people with dementia have:

- Increased delayed discharge from and readmission to hospital
- Premature admission to care homes
- A lack of appropriate services

Reports have consistently identified the causes of these failures of care include a widespread misunderstanding – and even fear – of dementia that leads people to believe that it is intrinsic to the aging process and untreatable. This leads people to believe – entirely mistakenly – that there is 'no point' in diagnosing the disease.

The problem is lack of information or misinformation

- People wait up to three years before reporting symptoms of dementia to their doctor
- 70 per cent of carers report being unaware of the symptoms of dementia before diagnosis
- 64 per cent of carers report being in denial about their relative having the illness
- 58 per cent of carers had believed the symptoms to be just part of ageing
- only 31 per cent of GPs believe they have received sufficient basic and post-qualifying training to diagnose and manage dementia
- 50 per cent of the public believe that there is a stigma attached to dementia
- people over 65 are more worried about developing dementia (39 per cent) than cancer (21 per cent), heart disease (6 per cent) or stroke (12 per cent)

Bearing in mind that about one-half of all cases of dementia have a vascular component (i.e. vascular dementia or mixed dementia), there is an opportunity to minimise the effects of dementia, or prevent it altogether for some people through health promotion messages on diet and lifestyle.

For those people with dementia now, and for those who will get it in the future, these expanded services will need to be pro-active offering early diagnosis and intervention support. People will need to be empowered to present themselves for diagnosis when signs and symptoms become apparent rather than wait. GPs and others need to know where they should send people for diagnosis.

Evidence suggests that

- Early provision of support at home can decrease institutionalisation by 22 per cent
- Even in complex cases and where the control group is served by a highly skilled mental health team, case management can reduce admission to care homes by 6 per cent
- Older people's mental health services can help with behavioural disturbance, hallucinations and depression in dementia reducing the need for institutional care
- Carer support and counselling at diagnosis can reduce care home placement by 28 per cent

- Early diagnosis and intervention improves quality of life of people with dementia and
- Early intervention has positive effects on the quality of life of family carers[21].

Based on the evaluation of the Croydon Memory Service it has been estimated that the development of memory clinics nationally would cost health and social services around £220 million a year or approximately £1m in extrapolated to NHS Trafford. This excludes the savings from reduced use of residential care that would be associated with implementing such services. In the longer-term, savings to social services could be of the order of £130 million a year or approximately £600k a year in Trafford. There would also be savings to individuals (i.e. for those who would fund their residential care privately). As a result, and as part of the PCT's refreshed Commissioning Strategic Plan, an additional investment of £500k is planned to expand this community mental health team provision.

This will result in an effective professional service with carers, friends and family all playing an important part in helping to identify dementia, by recognising changes in behaviour or personality earlier and with greater confidence.

It is not possible to diagnose dementia from a simple assessment and the expanded memory assessment and treatment services will ensure that such a diagnosis is made by fully excluding other possible causes and assessing a person's performance over time.

The process will include:

- **A detailed personal history** – This is vital to establish the nature of any changes that have taken place. It will almost certainly include a discussion with the main carer and any care service staff.
- **A full physical health assessment** – It is important to exclude any physical causes that could account for changes taking place. There are a number of other conditions that have similar symptoms to dementia but are treatable - for example, hypothyroidism and depression. It is important not to assume that a person has dementia simply because they fall into a high-risk group. A review of medication, vision and hearing should also be included.
- **Psychological and mental state assessment** – It is also important to exclude any other psychological or psychiatric causes of memory loss. Standard tests that measure cognitive ability are not usually applicable for people with learning disabilities, as they already have some cognitive impairment and may not have the verbal language skills that the tests require. As such expertise will be required in neuropsychology and neuropsychiatry
- **Special investigations** – Brain scans are not essential in the diagnosis of dementia, although they can be useful in excluding other conditions, or in aiding diagnosis when other assessments have been inconclusive.

Dementia Advisor Project

Age Concern Trafford is being funded by Trafford Council and PCT in 2009-11 to provide a dementia advisor project. In partnership with Trafford Carers centre this project provides two Dementia Advisers in line with Objective 4 of the National Dementia Strategy. An additional Carers Centre caseworker to focus on supporting carers of

people diagnosed with dementia, and a dementia advisor, based with Age Concern Trafford, working directly with the person with dementia. Both of these workers will focus on good quality information to carers and people with dementia and assisting them to access an early diagnosis. If these prove successful, longer-term funding is planned to sustain this development.

Dementia Peer Networks Project

On behalf of Trafford Council and PCT and funded by the Department of Health as a pilot site, Age Concern Trafford in partnership with Trafford Carers Centre, are developing in line with Objective 5 of the National Dementia Strategy, a range of peer networks for people with dementia and their carers. These networks will provide practical and emotional support, reduce social isolation and promote self-care, while also providing a source of information about local needs to inform commissioning decisions. Again, if these prove successful, longer-term funding is planned to sustain this development.

Health Checks for Carers

Trafford PCT in partnership with Trafford Council, Trafford Carers Centre and Crossroads have been successful in obtaining funding from the Department of Health to become one of a small number of successful local authorities that bid to become demonstrator sites for developing health checks for carers.

The aim of the demonstrator site is to work closely with GP practices to offer health checks to carers to support and promote their well-being in order for them to remain carers for longer. Although this project is for all carers, as part of the consultation process in the development of the national dementia strategy the issue of promoting the health and well-being of carers of people with dementia was highlighted. This project will therefore also provide vital support targeted at carers of people with dementia. Again, if these prove successful, longer-term funding is planned to sustain this development.

NHS Trafford is also currently already supporting the cross-cutting contributions from other local organisations with respect to additional PCT funding focussed on Safeguarding/ Mental Capacity Act, Psychiatric Liaison support into General Hospitals and increased support for Carers, and has already agreed to increase the Memory Assessment and Treatment Services and Community-based Dementia Units providing day care/support groups for more a further 30 people with dementia across Trafford in line with the National Dementia Strategy priorities and local assessed needs.

Learning from People's Experiences

What does the National Strategy consultation tells us?

There has been a clear and consistent message from those who have analysed current dementia care systems in England, and from the strategy consultation process, on the need for a public information campaign to change awareness and understanding about dementia. This includes expert opinion from people with dementia, carers, health and social care professionals and the Public Accounts Committee.

The potential for positive change is supported by data from a pilot awareness campaign by the Alzheimer's Society carried out in 2007. This achieved positive results with 78% of GPs believing that such a campaign would lead to people reporting symptoms earlier.

Emerging Key Messages for a National Public Information Campaign

- Dementia is a disease.
- Dementia is common.
- Dementia is not an inevitable consequence of ageing.
- The social environment is important, and quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease.
- Dementia is not an immediate death sentence; there is life to be lived with dementia and it can be of good quality.
- There is an immense number of positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia.
- People with dementia make, and can continue to make, a positive contribution to their communities.
- Most of us will experience some form of dementia either ourselves or through someone we care about.
- We can all play a part in protecting and supporting people with dementia and their carers.
- Our risk of dementia may be reduced if we protect our general health, e.g. by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury.

What does local consultation tell us?

Age Concern Trafford held consultations with groups and individuals who have dementia, or care for someone who does, and professional service providers. The key results from both avenues included support for services to bridge the gaps of:

- A lack of services after 5pm
- A lack of information on dementia and it's effects at diagnosis and after
- A lack of trained staff in home care, residential care and hospital
- A lack of co-ordination between services
- Clear pathways to and through services
- A shortage of specific dementia respite

- A shortage of opportunities for social interaction and activities, including in residential care and hospital
- A stigma to dementia in the community
- Lack of access to intermediate care and to end of life support

In addition people with dementia said they would like:
- Information to be given directly to the person with dementia as well as the carer i.e. they often felt "spoken about rather than spoken to"

The Carers Centre reported that the key areas of support requested and required by Carers are: **More Respite Care in differing forms, for example**:
- More day support
- More holidays
- More Respite in a Residential Home environment
- More sitting services in their own home
- More social activities
- More information and better communication from professionals

Making the Strategy Work!

Who is Responsible?

Partnership working is central to everything we do. The fact that you are reading this document indicates that you have an interest in improving the lives of people who have dementia and their families.

A Dementia Strategy Implementation Group has been formed, led by NHS Trafford with support and membership including Trafford Council, the wider Local Authority, Third Sector and other NHS partners. This group will monitor the implementation of the Strategy, making sure that, if completion of any goal becomes problematic, all stakeholders work harder to achieve it and if necessary escalation to more senior officers is expedited.

The PCT and Local Authority Strategic Commissioning Managers have a lead responsibility for implementation of the Commissioning Strategy, although as previously stated this will be done in partnership with Third Sector organisations and community groups, principally Age Concern.

When devising and implementing this Strategy we cannot underestimate the influence of the experiences of people and families living with dementia. It is now increasingly recognised that having a diagnosis of dementia does not mean that a person is unable to share their perspective and have a say in the health and social care system. Access to the direct experiences of people with dementia is ever more possible due to time taken to listen, earlier diagnosis and the availability of drug treatments. Further, personalised, high quality care requires understanding, and addresses the needs, of the people who may use the health and social care system. Actively involving people with dementia and carers in designing, developing and monitoring services will help to ensure commissioned services and others deliver what people need.

Reviewing the Strategy

The work of this Strategy will be reviewed by the Dementia Strategy Implementation Group to ensure that key objectives are met and the Strategy is on target.

Every six months, following Strategy approval, an Update Session will be delivered by the Lead Officers in an accessible venue. We will request that the outcomes of those sessions are circulated to the public in Trafford. These sessions will be open to all stakeholders.

An update report will be given to the Carers Centre to publish in the Carers Newsletter and to Age Concern Trafford to be publicised to all peer networks for people with dementia.

The Executive Member of the Council for Social Services will be updated regarding the progress of this Strategy by the Director of Social Services, and the Chief Executive of the Primary Care Trust by the Lead Commissioner for Mental Health/Disability Services.

Outcomes

The success of the strategy will be demonstrated by the fact that over the next three years people with dementia and their carers in Trafford will:

- Know where to go for information and support
- Know what services they can expect
- Are encouraged to and do seek help early for memory loss issues
- Get both high-quality and equality of care, wherever they live
- Are involved in decisions about, and have choice and control, over their care

In line with the Older People's Commissioning Strategy Action Plan, implementation of the local Dementia Strategy will support:

- Increased choice and control
- Enhanced information and prevention services
- Culturally appropriate services
- Social Inclusion
- Promoting independence
- High quality care
- Appropriate use of assistive technology
- A range of services including awareness raising, early diagnosis, low level interventions and post-diagnostic support (in particular expanded memory assessment and treatment clinics, day services, and breaks)

This will be apparent through both quantitative data demonstrating significantly more numbers of people supported better in Trafford and also evidence from a significant amount of personal stories illustrating the improved quality of life experiences evident for people with dementia in Trafford and their carers.

High Level Commissioning Delivery Plan - Mapped Against National Strategy

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROGRESS
1. **Improving public and professional awareness and understanding of dementia:** Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision	1.1 Develop and deliver a general public information / social marketing prevention campaign	**Trafford Council** **Trafford Primary Care Trust**	
	1.2 Inclusion of a strong prevention message: 'what's good for your heart is good for your head'	**Trafford Council** **Trafford Primary Care Trust**	
	1.3 Specific complementary local campaigns to national programmes	**Trafford Council** **Trafford Primary Care Trust**	
	1.4 Targeted campaigns for other specific groups (e.g. utilities, public-facing service employees, schools, and cultural and religious organisations) to enhance positive interactions with people with dementia	**Trafford Council** **Trafford Primary Care Trust**	
	1.5 Encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour	**Trafford Council** **Trafford Primary Care Trust**	
	1.6 Look at the development of a one stop shop for dementia patients and their families/carers providing information, counselling, activities, advocacy etc	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROGRESS
	1.7 Work towards the development of shared data systems to monitor services and good practice across Trafford	**Trafford Council** **Trafford Primary Care Trust**	
	1.8 Develop one point of contact for professionals and patients maximising role of dementia advisors and older people's community mental health teams	**Trafford Council** **Trafford Primary Care Trust**	
	1.9 Establish a dementia knowledge network and a forum for sharing good practice and joint training activities involving people with dementia, families, carers and professionals	**Trafford Council** **Trafford Primary Care Trust**	
	1.10 Develop a dementia passport / communication folder with all key patient information that staff can access easily, from this create a one page summary of the patient record to provide key information on admission and discharge	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROGRESS
2. **Good-quality early diagnosis and intervention for all.** All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area	2.1 Commission good-quality, locally available services, for early diagnosis and intervention in dementia, which have the capacity to assess all new severe cases occurring in Trafford through the expanded older people's community mental health teams	**Trafford Council** **Trafford Primary Care Trust**	
	2.2 Develop the capacity and location of responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can a) make the diagnoses well, b) breaks diagnoses sensitively of those affected, and c) provides individuals with immediate treatment, care and peer and professional support as needed	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS		LEAD OFFICER	PROGRESS
3. Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care	3.1	Review existing relevant information sets and packs with service users and carers	**Trafford Council** **Trafford Primary Care Trust**	
	3.2	Develop and distribute good-quality accessible information sets on dementia and services available which are of relevance at diagnosis and throughout the course of care	**Trafford Council** **Trafford Primary Care Trust**	
	3.3	Tailoring of the service information to make clear what local service provision is	**Trafford Council** **Trafford Primary Care Trust**	
	3.4	Ensure that information given to people with dementia and their carers is accessible, consistent and of a uniformly high standard	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS		LEAD OFFICER	PROGRESS
4. **Enabling easy access to care, support and advice following diagnosis**. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.	4.1	Evaluate current models of service provision as part of the review of existing contracts especially the Greater Manchester West NHS Foundation Trust Community Mental Health Team Services and also the Framework Re-tender programmes to revise the too common current practice across health and social care to 'discharge' patients once they are stable and a care package is in place. The result too often is that care consists of a number of quite expensive individual episodes, separated in time, provided by different people who do not necessarily have an ongoing relationship (and, therefore, some familiarity with the person and their condition), and often triggered as a result of a crisis.	**Trafford Council** **Trafford Primary Care Trust**	
	4.2	Commission a local dementia adviser service to provide a point of contact for all those with dementia and their carers, who can provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS		LEAD OFFICER	PROGRESS
	4.3	Dementia adviser contact to be made following diagnosis and to avoid duplicating existing 'hands-on' case management or care	**Trafford Council** **Trafford Primary Care Trust**	
	4.4	Provide a post-diagnosis support session for every patient and their family carers, and further evidence-based support groups and sessions	**Trafford Council** **Trafford Primary Care Trust**	
5. **Development of structured peer support and learning networks.** The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.	5.1	Determine current activity and models of good practice to inform commissioning decisions recognising one of the strongest messages from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and carers to exchange practical advice and emotional support	**Trafford Council** **Trafford Primary Care Trust**	
	5.2	Develop local peer support and learning networks for people with dementia and their carers that provide practical and	**Trafford Council** **Trafford Primary Care Trust**	

		emotional support, reduce social isolation and promote self-care, while also providing a source of information about local needs to inform commissioning decisions		
	5.3	Increased support to third sector services commissioned by health and social care	**Trafford Council** **Trafford Primary Care Trust**	
	5.4	Provide flexible joint training for health and social care staff through a new Joint Training Programmes Initiative	**Trafford Council** **Trafford Primary Care Trust**	
	5.5	Provide a minimum standard of training across the different sectors and settings where people with dementia receive services in line with national competency descriptions developed by Skills for Health and Care	**Trafford Council** **Trafford Primary Care Trust**	
	5.6	Follow up basic training with specific packages that reflect different workplace settings especially considering options for residential and nursing care homes as part of the quality improvement programme	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROGRESS
5. **Development of structured peer support and learning networks.** The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.	5.7 Develop education programmes on dementia awareness in schools	**Trafford Council** **Trafford Primary Care Trust**	
	5.8 Develop local dementia training for GPs following planned Conference for GPs in Trafford - 29th Sep 2010 led	**Trafford Council** **Trafford Primary Care Trust**	
	5.9 Support dementia training in professional curriculum teaching and placements	**Trafford Council** **Trafford Primary Care Trust**	
	5.10 Develop mandatory minimum level dementia awareness courses for commissioned acute hospital, primary care and care homes services, including consideration of Safeguarding issues	**Trafford Council** **Trafford Primary Care Trust**	

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROGRESS
6. Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.	6.1 Implement *Putting People First* personalisation changes for people with dementia, utilising the Transforming Social Care and Innovation Grant programmes, as well as additional Direct Payments/personal budgets support packages as part of the Older People's Commissioning Strategy.	**Trafford Council** **Trafford Primary Care Trust**	
	6.2 Expand the recognised evidence base for effective specialist services to support people with dementia at home (e.g. making greater use of the Cognitive Stimulation Therapy resources within existing commissioned services)	**Trafford Council** **Trafford Primary Care Trust**	
	6.3 Commissioners to implement best practice models thereafter For those people with dementia who live in their own homes the experience is of home care delivered by a	**Trafford Council** **Trafford Primary Care Trust**	

	rota of non-specialists who are therefore less able to observe and appreciate the significance of small changes in behaviour and cognition that are the markers for the progression of disease that a smaller, more specialised team are able to do. An additional consideration is that succession of different people presents challenges in terms of communication for someone who is increasingly confused and so a barrier to efficient and effective communication – and care. Finally, the lack of insight in dementia may mean services are refused but this is less likely when there is a coherent focussed approach from a single known individual or group of people. We therefore wish to make the current generic home care resource work as well as it can for people with dementia, augmented by the training and information and the accurate diagnoses generated by other elements of the strategy.		
7. **Implementing the Carers' Strategy**. Family carers are the most important resource available for people with	7.1 Ensure that the needs of carers for people with dementia are included as the strategy is implemented	**Trafford Council** **Trafford Primary Care Trust**	

dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected	7.2 Promote the development of breaks that benefit people with dementia as well as their carers and apply same approach to expanded Extra Care/ Intermediate Care options	**Trafford Council** **Trafford Primary Care Trust**	
8. **Improved quality of care for people with dementia in general hospitals.** Identifying leadership for dementia in general hospitals, defining the care pathway for dementia	8.1 Identify a senior clinician within the general hospital to take the lead for quality improvement in dementia in Trafford General and Wythenshawe Hospitals within the context noted below. Who Cares Wins estimates that a typical district	**Trafford Primary Care Trust**	

there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.	general hospital with 500 beds will admit 5,000 older people each year and 3,000 will suffer a mental disorder. On average, older people will occupy 330 of these beds at any time and 220 of these will have a mental disorder (102 with dementia). Equally, the National Service Framework for Older People estimates that up to 70 per cent of acute hospital beds are currently occupied by older people and up to a half of them may be people with cognitive impairment, including those with dementia and delirium. The majority of these are not known to specialist health services, and are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation. This impact is not widely appreciated by clinicians, managers and commissioners. In terms of excess cost, the NAO estimated there to be in excess of £6 million per year		

	in an average general hospital		
	8.2 Develop an explicit care pathway for the management and care of people with dementia from primary care to in hospital, led by that senior clinician and Integrated Care System Mental Health project task group	**Trafford Primary Care Trust**	
	8.3 Gather and synthesise existing data on the nature and impacts of specialist liaison older people's mental health team support to work in general hospitals	**Trafford Primary Care Trust**	
	8.4 Commission additional specialist liaison in the older people's mental health team to work in general hospitals	**Trafford Primary Care Trust**	
9. **Improved intermediate care for people with dementia.** Intermediate care which is accessible to people with dementia and which meets their needs.	9.1 Continue with plans to commission both expanded day and in-patient service options to respond all too common experienced delayed discharges from hospital and are too often discharged from hospital to a care home, in part because of an assumption that this is the best – or only – safe option (especially where capacity and capability to	**Trafford Primary Care Trust** **Trafford Council**	

	deliver good quality home care is also lacking) but also to relieve pressures on acute beds.		
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.	10.1 Monitor the development of models of housing, including extra care housing, to meet the needs of people with dementia and their carers. More recently the importance of flexible care packages in meeting the needs of people with dementia in extra care housing has been demonstrated. Many areas are now offering this sort of flexible, responsive care package through floating support services. Many residents with dementia in sheltered or extra care housing have complex health and care needs.	**Trafford Council** **Trafford Primary Care Trust** **Trafford Housing Trust**	
	10.2 Staff working within housing and housing-related services to develop skills needed to provide the best quality care and support for people with dementia in the roles and settings where they work	**Trafford Council** **Trafford Primary Care Trust**	
	10.3 Keep a watching brief	**Trafford Council**	

	over the emerging evidence base on assistive technology and telecare to support the needs of people with dementia and their carers to enable implementation once effectiveness is proven	**Trafford Primary Care Trust**	
11. Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.	11.1 Support the PCT Safeguarding and CHC Nurse Leads to identify of senior staff members within the care home services to take the lead for quality improvement in the care of dementia in all commissioned care home service enabling significantly more homes to move up from adequate CQC ratings	**Trafford Council** **Trafford Primary Care Trust**	
	11.2 Develop a local strategy for the management and care of people with dementia in care homes, led by senior staff. A third of people with dementia live in care homes and at least two thirds of all people	**Trafford Council** **Trafford Primary Care Trust**	

	living in care homes have a form of dementia. This state of affairs has not been planned for, either though commissioning services or through workforce planning. The need for workforce development is profound, and together with practical training.		
	11.3 Implement policy regarding the appropriate use of anti-psychotic medication for people with dementia with the support of the newly commissioned Mental Health Pharmacist Clinical Advisor	**Trafford Council** **Trafford Primary Care Trust**	
	11.4 Commission additional specialist in-reach services from the expanded Older People's Community Mental Health Teams to work in care homes targeting reductions in dementia and depression-related	**Trafford Council** **Trafford Primary Care Trust**	

	problems		
11. Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.	11.5 Produce revised specifications for commissioned in-reach services such as primary care, pharmacy, dentistry, etc into care homes. Such in-reach services should enhance the quality of care in care homes by providing a regular forum for discussion between nursing staff, GPs and mental health teams to identify and manage the mental health problems of residents. The result of such support are likely to include: • decrease in the use of anti-psychotic medication • a reduction in common unmet needs in older people: memory, eyesight/hearing, continence, mobility and psychological distress	**Trafford Council** **Trafford Primary Care Trust**	

	• a decrease in the number of people in care homes with case level depression and/or anxiety • Earlier detection of illness, which may enhance the effectiveness of treatment. This may impact positively on residents health and quality of life and also reduce the number of avoidable emergency hospital admissions • Residents requiring fewer GP contacts, and a reduction in the number of days in psychiatric inpatient facilities. This may produce a cost saving for the NHS.		
	11.6 Enable better and readily available guidance and training for care home staff on best practice in	**Trafford Council** **Trafford Primary Care Trust**	

	dementia care		
	11.7 Increase the availability of meaningful activities in line with evidence-based Cognitive Stimulation principles. Evidence from the Alzheimer's Society Home from Home report suggests that: • 54 per cent of carers reported their relative did not have enough to do in care homes • the typical person in a care home spent just two minutes interacting with staff or other residents over a 6 hour period of observation (excluding time spent on care tasks) • the availability of activities and opportunities for occupation is a major determinant of quality of life affecting mortality, depression, physical function and behavioural symptoms,	**Trafford Council** **Trafford Primary Care Trust**	

	but that these are seldom available; and • Staff enjoy providing opportunities of activity and occupation and would like to be able to do more of this within their work but do not feel they have the time.		
	11.8 Develop increased personalised budgets options to fund respite care as needed	**Trafford Council** **Trafford Primary Care Trust**	
	11.8 Ensure advocacy services are appropriate including supporting plans to re-tender the existing specialist provision as a single more coherent Trafford Citizens across-client groups service	**Trafford Council** **Trafford Primary Care Trust**	

12. **Improved end of life care for people with dementia.** People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.	12.1 Initiate demonstration projects, pilot and evaluate models of service provision prior to implementation, given the current lack of definitive data in this area	**Trafford Council** **Trafford Primary Care Trust**	
	12.2 Develop better end of life care for people across care settings which reflects their preferences and makes full use of the planning tools in the Mental Capacity Act	**Trafford Council** **Trafford Primary Care Trust**	
	12.3 Develop local end of life care pathways for dementia consistent with the Gold Standard framework as identified by the End of Life Care Strategy	**Trafford Council** **Trafford Primary Care Trust**	
	12.4 Ensure that palliative care networks, developed as part of the End of Life Care Strategy, support the spread of best practice on end of life care in dementia	**Trafford Council** **Trafford Primary Care Trust**	
	12.5 Develop better	**Trafford Primary Care**	

	pain relief and nursing support for people with dementia at the end of life	**Trust**	
13. An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.	13.1 Local workforce training and development strategies to take on board the implications of the dementia strategy	**Trafford Primary Care Trust** **Trafford Council**	
	13.2 Work with senior professional representatives across services involved in professional and vocational training and continuing professional development to reach agreement on local programmes to help meeting the core competencies required in dementia care	**Trafford Council** **Trafford Primary Care Trust**	
13. An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have	13.3 Work with senior professional representatives across services to consider how to adapt their curricula and requirements to include these core competencies in pre- and post-qualification and	**Trafford Council** **Trafford Primary Care Trust**	

dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.	occupational training		
	13.4 Support changes to inform any review of national health and social care standards	**Trafford Council** **Trafford Primary Care Trust**	
	13.5 Commissioners to specify necessary dementia training for service providers	**Trafford Council** **Trafford Primary Care Trust**	
	13.6 Improve continuing staff education in dementia	**Trafford Council** **Trafford Primary Care Trust**	
14. A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy.	14.1 Formalised support for the Trafford Living Well with Dementia joint strategy, and be integrated as part of NHS Trafford refreshed Commissioning Strategic Plan and Trafford Council's Putting People First Transformation programme, including the Older People's revised Commissioning Action Plan	**Trafford Council** **Trafford Primary Care Trust**	
	14.2 The joint commissioning strategy for dementia will reviewed and continue to be based on the Joint Strategic Needs Assessment that will specify the outcomes required and should be	**Trafford Council** **Trafford Primary Care Trust**	

	developed in consultation with people with dementia and their carers		
	14.3 Joint commissioning strategies will need to take account of people's needs for both mainstream and specific services. They will need a community focus, linking into Local Area Agreements and the development of sustainable communities and an individual focus, drawing on the use of personal budgets and the commissioning of self-directed support	**Trafford Council** **Trafford Primary Care Trust**	
15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers. Inspection regimes for care homes and other services that better assure the quality of dementia care provided.	15.1 Develop an understanding what it is like to live in and use a service. This is crucial to understanding the quality of outcomes that people experience. Specific efforts should be made to ensure that, where relevant the monitoring of the experience of those with more advanced dementia or compromised communication	**Trafford Council** **Trafford Primary Care Trust** **Care Quality Commission**	

	needs is included		
	15.2 Family carers, regular visitors and staff points of view should also be taken into account during service assessments	**Trafford Council** **Trafford Primary Care Trust** **Care Quality Commission**	
	15.3 Support provided to the planned CQC use of the SOFI (Short Observation Framework for Inspection) tool which allows inspectors to have a structured way of observing people's experiences and enables them to make judgements beyond routine care practice	**Care Quality Commission**	
16. A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.	16.1 Support the plans nationally for the Medical Research Council (MRC) with DH to convene a summit of parties interested in dementia research	**Department of Health** **Medical Research Council**	

KEY OBJECTIVES	ACTIONS	LEAD OFFICER	PROCESS
17. Effective national and regional support for implementation of the Strategy. Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.	17.1 Support the Department of Health's plans to provide support for all those involved in implementing the strategy locally to ensure its delivery, particularly for those areas where services are less developed	**Department of Health** **Trafford Council** **Trafford Primary Care Trust**	
	17.2 Participate with other localities will need help with 'getting started', particularly if little attention has previously been given strategically to the needs of people with dementia – this includes for example the national pilot programmes on the Dementia Peer Networks and Carers Health Checks	**Department of Health** **Trafford Council** **Trafford Primary Care Trust**	
	17.3 Support the plans for the regional support teams convened to support local implementation	**Department of Health** **Medical Research Council**	

	17.4 Provide information on an annual basis from both the NHS and social care services to review the extent of current services for people with dementia and their carers, and to track these over time to monitor progress on implementing the Strategy	**Trafford Council** **Trafford Primary Care Trust**	
	17.5 Support the national baseline measurement of services will be established	**Department of Health**	
	17.6 Support any specifically commissioned research, evaluations and data from demonstrator sites will support the implementation of the Strategy	**Department of Health**	

Funding

To Be Confirmed – No Additional Funding currently planned other than that previously agreed through NHS Trafford's Refreshed Commissioning Strategic Plan and Trafford Council's Putting People First Transformation Programme

Strategy Summary

The drive to improve services for people with dementia is of national importance. This ambition is detailed in the intentions, objectives and plans outlined in this document. Trafford have taken the National agenda and developed it further to ensure that the outcome of this Strategy will be actual benefits and positive life experiences for people with dementia and their carers.

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Appendices

Appendix1

Age Concern Service User & Carer Consultation Event on Dementia - 29 March 2010
Results of the workshops

1. **Where the person with dementia remains in their own home, what support would you want to see in Trafford for them and their carers?**

   - Training for carers around dealing with dementia, caring for someone with dementia
   - More information for carers/family about dementia and how it will progress
   - Emergency backup help – a crisis contact point, especially outside normal office hours
   - Good quality and flexible sitting services
   - More respite with flexibility – and specialised beds for dementia
   - More specialist dementia day support
   - Ensuring all staff trained appropriately – especially home care providers, and respite staff
   - Access for carers to go and look at/spend time at the service provided for cared for e.g. day support
   - Domestic help for carer e.g. cleaning, shopping etc
   - GP's to have knowledge and understanding of services available e.g. Carers Centre/Age Concern.
   - Access to support before crisis, with practical information on how to cope
   - Companionship/Befriending – matching both for person with Dementia and Carer
   - Services for person with Dementia living alone – what happens to them when no carer/family to support
   - Enable Good neighbouring – change in community attitude (OK to intervene before crisis)
   - Poster campaign – raise awareness of dementia
   - Raise intergenerational awareness of dementia
   - More Carers breaks
   - Phone call service to/for carers
   - Duplicate letters to primary carer of person with Dementia – e.g. re GP appointments etc. so that appointments and other things not missed.
   - Shopping service taking person with Dementia into community
   - Bathing support
   - Continuity of Social Worker/Home Carers etc.
   - More info about specifics rather than general

- Peer support for carers/ person with Dementia
- More dementia awareness workshops
- More communication, between agencies, know about each others services, pathways and signposting
- Continued contact from Social Services. Regular not yearly review over phone.
- Trigger Social Services on diagnosis
- Work with person with Dementia not label them
- Adequate time for Home Care Staff to spend with person with Dementia
- Dedicated Home Care Teams for dementia
- Appropriate Day Support to meet person with Dementia needs
- More peer support
- More medical advice and assessment
- More PCT involvement
- Recognition of undiagnosed cases
- Safety – telecare facilities
- Health screening programme for memory loss (like cancer screening already in place)
- Assisted support to access community
- Care packages which are person centred and not time specific
- Breaks for carers and cared for – high quality, flexible and responsive to need

2. Where the person with dementia is in hospital, what support would you want to see in Trafford for them and their carers?

- Trained and dedicated nursing staff specifically for dementia
- Specific ward for people with dementia
- Volunteer service – supporting, befriending, helping to eat etc.
- Leaflet/card explaining what cared for can't/can do
- EARLY DIAGNOSIS
- More information at diagnosis and after
- Referrals on to appropriate services
- Training for carer
- Someone to talk to for both person with Dementia and Carer
- Training for ALL hospital staff in dementia awareness and how to deal with people with dementia
- Wider visiting times for families of person with dementia
- More understanding of dementia from doctors and nursing staff
- More activity/stimulation whilst in hospital
- Support with mealtimes

- Support with change of environment home – hospital. Person with Dementia needs reassurance.
- Stop false assumptions of capacity (or lack of it) by professionals.
- Better discharge arrangement – slow and monitored, get back into routine and get used to care services
- Better transport for carers/family to visit
- Ensure hospital staff awareness of dementia – if person with Dementia in hospital for other reason e.g. fall
- Increase awareness with schools, police, fire service etc.

3. **Where the person with dementia is in a residential or nursing home, what support would you want to see in Trafford for them and their carers?**

- Training for all home staff
- Time allowed for staff to get to know the person
- Activities and occupation and stimulation – support retention of social & practical skills
- Quality management – not just about profit
- Cultural training – providing culturally appropriate care
- Allowing risk taking when appropriate
- Remaining in same care home – no transfer
- Recognise different stages of dementia and care accordingly including suitable activities
- Continuity of staff caring for person with Dementia
- Listen to carers they know the person
- Opportunities to get outside the home
- Change home environment – specialist areas or specialist homes
- Home checked regularly and without warning
- Advice for carers on what needs to be dome before person with Dementia loses mental capacity
- Benchmark services – good practice sharing
- Memory book/life history album part of care package
- Consistency of approach in care home
- Outside groups going in to do activities/befriending
- Support to remain involved in community
- No use of medication simply to keep residents quiet!
- Use gardens
- Flexible bed time – wake up time.
- Familiar things around them – family picture – piece of furniture etc.
- Family to feel welcome at care home

4. **Where the person with dementia is coming to the end of life, what support would you want to see in Trafford for them and their carers?**

- Compassion, respect, dignity
- Same rights to services as other illnesses
- Involvement of family
- Specialist nursing/care workers (like Macmillan for cancer)
- Correct faith rituals carried out
- Find out what people want before they lose capacity
- Preparing the carer for what needs to happen, know their rights and person with Dementia rights etc.
- Emotional support – bereavement counselling
- Keep in home/care home, not hospital if possible
- Give physical contact to show affection, support, and love – always carry on talking to them, using their name.
- Honesty – talk about it early
- Counselling
- Individual's needs taken into account
- Have a 'Dementia Standard' to Quality Mark services.
- Pre-End of Life counselling as part of care package
- 'Passport' details of living will, wishes etc.
- Promote available services widely – not wait for carer to ask
- Same choices as for people without dementia
- Support carers to get back into community after death of person with Dementia (or preferably before death so already got other aspects to life beyond 'being a carer' – loss of caring leaves big gap if no other life

Appendix 2

Dementia Services in Trafford Multi-Agency Planning Day - 19 April 2010

Summary Results of the Workshop

Agenda

- Understanding the Dementia Strategy
- Context
- Agreeing key themes of the Trafford strategy
- Agreeing priorities and quick wins, short term and longer-term programme
- Summarising a shared agenda for action and links with NDS
- Taking stock
- Planning the way forward including recognising possible blocks
- Identifying blocks and what if any major disagreements

What should be in strategy?

- Joint working
- Clear over-aching aims
- Style of working – person/customer-focussed
- Assertive – tackling stigma
- Clearer routes to access info and support
- Admissions/Discharges – Care pathways
- Crisis support – Respite / Practical
- Understanding no's – volumes – demand
- Public awareness
- Early diagnosis and support
- Training esp. primary care differential depression
- End of life – palliative care
- Agreeing 1st steps

Taking Stock – Organisation/Planned/Whole System Approach

- **Over-Arching Themes**
  - Promoting independence to be reinforced
  - Person-centred and need-based services
  - Crisis prevention vs. crisis-led services
  - Promote better understanding of illness
  - Proactive carers
  - Poor info flows between
  - Good pockets but people don't know about it (e.g. handy help, carer help lines, telecare, dementia advisors, day services, peer networks)
  - Good work despite system
  - Need dedicated dementia respite beds
  - No out-of-hours support except EDT
  - Early intervention
  - Fragmented – Lack of joint working
  - Services work for people who are assertive
  - Extra care models positive – Elkin/Newhaven
  - Lack of specialist services/homes in Trafford

- **Service user journey**
  - Confusing at beginning to access services - Inconsistent
  - Identification of probs difficult – Hard to get in / lack of promptness
  - Bewildering
  - Hit & miss
  - Lack of knowledge from GPs
  - Confidence
  - Extremes of support from v little to overload
  - Limited use of technology – telecare options
  - Poor physical care/checks – double discrimination
  - Minders in bays vs. structured intensive support e.g. wandering
  - Flagging pts needed to manage care journey and support e.g. cleaners
  - When crisis? Who call and how quick will get support
  - In hospital do health care needs get met or missed because of dementia issues overlay

- **Carers**
  - Tired
  - Confused re their relative and dementia
  - Needing respite – short breaks
  - £ and other info / eligibility ignorance
  - Consistency
  - Fear about going into care and homes
  - Mistrust of local strategies – improving services vs. cuts
  - Little support after 5pm and at w/e's

- **Staff / practitioners**
  - Keen and committed wkforce
  - Don't want to label
  - Older people gps into hospital has changed alot
  - Training and changes can help
  - Blocked exclusion eligibility criteria for rehabilitation/intermediate care – if confused/wandering/needing long-term support cf reablement
  - Assessments reactive
  - Skill mix based on physical vs. mental capacity
  - Slow change – There is a future and need to listen
  - Waiting for info and assessments – Watching people stuck and deteriorating
  - Bureaucracy – confusing for everyone
  - Significant variations between care settings/leadership
  - Rehabilitation not a priority cf Section 5's with cash penalties
  - Need for more mentoring for excellence – champions to lead by e.g.
  - Families who argue
  - Liaison services very positive and day centres
  - ? No set standards for memory cafes/services
  - Lack of directory
  - LD care pathway positive cf other areas

How much is the above due to systems vs. people styles/ways of working?

System / Behaviour / Why do the things that Work? / Comparisons / Root causes

- ? Joint
- Significant variations even accessing GPs
- Critical decision points – referrals to physicians vs. memory services
- Need for clear action plans – monitoring systems/scorecards
- Passion
- Responsibility being personally owned
- Increasing focus on teams cf individuals

Possible Actions That Can Be Planned and Agreed Now

1. **Quick Wins (petty cash/resource-light)**
    a. Publicise BlueSCI websites and add in
    b. Targeted support to carers via library connections – public places
    c. Core Group - Regular follow-up meetings to update/implement dementia strategy – 2-way communications linked into commissioner-led contract review mtgs mandated
    d. Improved GP awareness/recognition of carers - campaigns
    e. Training across services re resources available
    f. Equality impact assessments
    g. National campaigns piggy-back
    h. Benchmarking services uses/pts across GPs and practices
    i. Consultants direct referrals to memory services

2. **Short-Medium Term Changes (Strategic redesign and service improvements – Realism!)**
    a. Stream-lined infrastructure and communications esp. with GP to update/implement dementia strategy
    b. List and Directory of Services – Access improved
    c. Flagging of patients/carers as they access services esp. hospitals and linking vulnerable people's liaison support
    d. Increase info/training/education for people to understand what leads to crisis/ problems
        i. Medical care pathways
        ii. Social care pathways
    e. Change exclusion criteria for intermediate care services and better admission/discharge processes
    f. Embed dementia wk into/links to CHD/Respiratory/Cancer pathways and plans
    g. GP QOF system changes – Incentivise early identification of dementia patients
    h. Collate/identify unmet needs
    i. Review resources and current service specs
    j. Cultural changes – Stigma – BME
    k. In-reach into residential care and nursing homes and admission protocols
    l. What does a pathway mean?

3. **Longer-Term Investments (Real £ and Cultural shifts)**
    a. Make pathways work
    b. Increased MDT approach – systems and training
    c. Change in the early-onset assessment/diagnostics/care process
    d. Increase focus on prevention – lifestyle, alcohol, health checks
    e. Increase targeted Reablement-Respite services – In-Control reinvent and realign
    f. Old traditional hospital and day services don't work – increase alternatives

g. Increase crisis support service options better
h. Mental Capacity Act – Personal Control options
i. Regular auditing/monitoring systems
j. Developing Admiral services in Trafford
k. Increased crisis services
l. Map back to National Strategy

How will we know we have succeeded? 3 Years On

- More people supported in better ways for less money (less than double)
- More people accessing preventable services and early diagnosis – Better access
- Integrated care and service systems
- Carers feeling better supported
  - Knowing where to go and right info at right time
  - Positive responses/feedback – less crisis/stress/experiences
  - Crisis
- Increased variety of service options
- Trafford reputation enhanced
- Seamless care pathways and eligibility not used as much to opt people out
- Staff feeling more confident and competent

Identified Priorities for Action (mapped against National Dementia Strategy)

1. Consistency across providers and common practice approaches across service providers
   - A joint Commissioning Strategy for dementia
   - Improve the quality of care for people with dementia in care homes
   - Improve the quality of care for people with dementia in general hospitals
   - An informed and effective workforce for people with dementia
   - Improve assessment and regulation of health and care services and of how systems are working

2. Enhanced service coordination
   - Good Quality, early diagnosis, support and treatment for people with dementia and their Carers, explained in a sensitive way
   - Easy access to care, support and advice after diagnosis

3. Better service information
   - Good quality information for people with dementia and their Carers

4. Overcoming gaps
   - Demographics – Needs assessment
   - Improve community personal support services for people living at home
   - Memory clinics
   - Improve intermediate care for people with dementia
   - Crisis / out-of-hours
   - Improve end of life care
   - Shifting resources from reactive to prevention services

5. Improving access and prevention/early intervention
   - Consider how housing support, housing – related services, technology and telecare can help support people with dementia
   - Develop structured peer support and learning networks
   - Implement the New Deal for Carers

6. Public education / Tackling stigma
    - Raise awareness of dementia and encourage people to seek help
    - Effective links with national and regional support for local services to help them develop

Possible Blocks to Taking Action

- £
- Capacity
- Attitudes
- Commitment
- Communication
- No GPs / Hospital Consultants present?

The Key Dementia Pathway Points

At moment no integrated pathways exist

- Prevention
    - Eating
    - Drink
    - Work and keeping busy

- Early Identification of Cognitive Decline
    - Public health / education
    - Assertive Primary care screening
        - Vulnerable groups – lifestyle, LD, people missing appts
        - Differential diagnosis older people depression/physical health complications
    - Carers decisions training
    - Non-stigmatising venues / means

- Short-term Support
    - Memory clinics - Prescriptions
    - Peer Support
    - Dementia advisors
    - Carers centre/forum
    - Crisis support inc Emergency Respite

- Longer-term Support
    - Memory clinics – Links to Older People CMHTs
    - Peer Support
    - Dementia advisors
    - Carers centre/forum/replacement care & support to manage breakdowns
    - Flagging pts across primary/secondary care
    - Liaison support into hospital care
    - Crisis support inc Emergency/Planned Respite – Break options
    - Assessment and Reablement / Personalisation
    - Individual home care packages
    - Intermediate care options – 6 weeks+
    - Extra care homes
    - Safeguarding into home care / residential markets – monitoring
    - Nursing care and CHC
    - End of Life
    - Reducing poor medication prescribing

Appendix 3

National Dementia Strategy – Easy Read

Appendix 4

Alzheimer's Society Presentation on the Dementia Support Needs in Trafford

Appendix 5

Consultation Presentation on the local Joint Trafford Dementia Strategy

Appendix 6

Trafford Older People's Commissioning Strategy Action Plan (2009-11)