



Manchester Dementia Strategy

**Responding to the health and social
care needs of people with dementia
in Manchester**

2009 - 2012

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1: Introducing the Strategy

It has become increasingly clear both locally and nationally that dementia is one of the biggest challenges facing the health and social care economy. At the end of 2007 the joint Policy and Operations Group (POG) for Older People commissioned a piece of work to produce a Dementia Strategy for Manchester. A multi-agency working group was set up to do this work Membership of this group is given in Appendix 1.

Although dementia can affect adults at any age, it is most common in older people and becomes more prevalent with increasing age. The population of older people in the UK is set to rise steadily both in proportionate and in absolute terms over the next few decades.

The likelihood of experiencing dementia doubles every five years in later life. By the age of 95, one in three people are affected.

National policy background

Until recently, dementia has suffered from poor awareness and understanding, combined with the stigmas attached to both mental illness and old age. For a number of years, the voluntary sector has highlighted concerns over the appropriateness and quality of health and social care for people with dementia. The Audit Commission's *Forget me not* report ¹ also found that GPs tend to treat the diagnosis and treatment of dementia with a lack of urgency.

Dementia received some mention in the the 2001 *National Service Framework for Older People* (NSF) ², a ten-year programme to set new national standards and service models of care across health and social services for all older people.

Standard 7 of the *National Service Framework for Older People* states that older people who have mental health problems should have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and their carers

Clear policy guidance on how health and social care should commission and provide specialist services for older people with mental health problems (including dementia) in an integrated way was published in 2005 under the title,

¹ Forget me not. Audit Commission. 2002

² National Service Framework for older people. DoH. March 2001

*Everybody's Business*³. Essentially, this gave direction to the broad, positive statements in the National Service Framework.

The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE)) have also issued joint guidance ⁴ on the treatment and care of people with dementia in health and social care. For the first time, healthcare professionals working within the NHS will be following the same guidelines as social workers and care workers in nursing homes.

However, a 2006 review of the effectiveness of the NSF ⁵ found evidence of continued inadequacies in health and social care for older people with mental health problems and a more recent report by the National Audit Office ⁶ suggested that dementia had not been receiving specific high priority within the NSF programme.

2007 saw a critical mass of research findings and reports developing, with two key reports - from the Alzheimer's Society⁷ and the National Audit Office ⁸ - highlighting the significant and urgent challenge to health and social care presented by dementia – particularly in light of their prediction that there will be over a million sufferers in England by 2025.

The Government followed this with an announcement in August 2007 that it would produce the first ever national dementia strategy, to meet the demographic challenge of increasing numbers and the failure of the current system to serve dementia sufferers and their families well. Work was co-ordinated by CSIP and involved all the key stakeholders from the health and social care fields. The Strategy was published in February 2009.

It looks at 3 key areas

1. Improved awareness
2. Earlier diagnosis and intervention
3. Higher quality of care

There are 17 objectives covering these areas. The situation in Manchester is measured against these in Chapter 6.

A Strategy for Manchester

Over 4,000 people in Manchester have dementia and numbers are projected to rise to 5, 000 by 2029.

³ Everybody's Business. Care Services Improvement Partnership. 2005

⁴ Published November 2006

⁵ Living well in later life – a review of progress against the National Service Framework for older people. CSCI et al. 2006

⁶ Improving services and support for people with dementia. National Audit Office. July 2--7

⁷ Dementia UK, Alzheimer's Society. February 2007

⁸ Improving services and support for people with dementia. National Audit Office. July 2007

It is essential that Manchester City Council, NHS Manchester, the Mental Health and Social Care Trust (MMHSCT) and voluntary and independent sector organisations work and plan together to be able to respond to local demographic and service challenges and to the issues also being considered as part of the national strategy.

The local strategy is intended to cover NHS and Adult Social Care (ASC) as well as those voluntary, commercial and charitable organisations from which services may be commissioned.

It is intended that the strategy will cover a three-year period 2009 – 2012.

This strategy is primarily intended to guide planning and commissioning by NHS and Adult Social Care staffs although it may also be of interest to other organisations, service users and carers of people with dementia.

The document contains:

- an analysis of the most common forms of dementia and their impact on the individual (Chapter 2);
- a summary of population and prevalence trends nationally and in Manchester (Chapter 3);
- an overview of current resource availability and analysis of what else may be needed (Chapter 4);
- the results of 2 surveys carried out with staff and service users and carers between April and July 2008 (Chapter 5);
- an analysis of how Manchester measures up to the National Strategy objectives (Chapter 6);
- gaps (Chapter 7);
- recommendations (Chapter 8);
- appendices which provide supporting information (Chapter 9).

2: What is Dementia? Different conditions and their impact on society and services

The concept of dementia

Dementia is a loss of brain function; it is not a single disease. Instead the word refers to a group of illnesses that affect memory, behaviour, learning and communication skills.

From its beginning, the concept of dementia has been close to that of “madness” and the word carries a connotation of insanity. However, our perception has been changed by our increased understanding of the neurological changes underlying dementia and the increased weight being given to the personal experience of this group of illnesses. In this section, the emphasis will be on offering brief descriptions of a number of conditions each of which is a main type of dementia.

Dementia as a cluster of symptoms is characterised by impairment in memory and other higher brain functions. Dementias are conditions where there is deterioration from a person’s previous intellectual and functional abilities, so symptoms may include changes in the ability to use language, to manipulate objects and failures of recognition of people or places, as well as memory loss. Non-cognitive symptoms can include changes of mood, personality and behaviour, abnormal mental states including unusual beliefs and perceptions such as hallucinations or illusions. Because the dementias are degenerative neurological disorders, some also involve deterioration of other aspects of neurological function, such as movement disorders.

Dementia subtypes

Introduction

There are many different dementing illnesses. For the purposes of this strategy the most common types will be described. Estimates of the frequency of occurrence of these illnesses nationally and in the Manchester population are given in Chapter 3.

Alzheimer’s disease

Alzheimer’s disease is the most common dementing disorder. Disturbances of recent memory function are the typical symptoms that lead to a suspicion that a person has developed Alzheimer’s disease. A person may repeat themselves in conversation, perhaps repeating the same question or forgetting recent conversations. The onset of the illness is usually gradual and symptoms

develop over a period of some years. This gradual onset may be so insidious that in the early stages symptoms are ignored or misinterpreted. They are thought to be simply “normal aging” or perhaps depression. Symptoms are typically present for between 1-3 years before a patient or family member might seek help. As with all dementing illnesses there may be a period where a person is aware of a change in ability or function before they talk to others about their concerns.

In Alzheimer’s disease symptoms are typically those of cognitive decline, memory is impaired with significant deficit in new learning but eventually the ability to retrieve long-term information is also impaired. Disturbance of language function is frequently seen in Alzheimer’s disease, both with deficits in naming and also in word fluency. Disturbances in the ability to recognise objects and people occur as later symptoms in the illness, although may in themselves be presenting symptoms.

Vascular Dementia

Vascular dementia is the second most common cause of a dementia syndrome accounting for between 10 and 50% of cases depending upon the geographical area, the population and the diagnostic criteria used. Vascular dementia occurs as a result of disease in the circulation of blood to the brain. This may occur as a result of a major stroke, as a result of multiple small strokes or following a deterioration of nerve cells which have a chronic reduction of blood supply. There is an association between vascular dementia and the development of Alzheimer’s disease. This association probably has a genetic basis. It is likely that at least 20% of those who have a diagnosis of vascular dementia also have Alzheimer’s disease.

The symptoms of vascular dementia include a so called “cognitive syndrome” including memory loss, difficulty carrying out complex actions, slowed information processing and a mood and personality change. These may be associated with behavioural and psychological symptoms of dementia which, in vascular dementia particularly, includes mood change, depression, anxiety and psychomotor retardation, together with hallucinations and delusions. Because vascular dementia is associated with strokes it is common that signs of focal brain disease are identified, these might be motor signs such as motor deficits, decreased coordination or abnormal reflexes. There might also be problems with speech, swallowing or vision. These diverse symptoms may often begin suddenly indicating a focal injury. Such abrupt changes are part of the pattern of deterioration described as a step-wise deterioration.

Fronto-Temporal Dementia

Fronto-temporal dementia is one of a group of dementias which develop as illnesses with localised symptoms, eventually progressing into a more generalised deterioration. It is characterised by changes in behaviour, personality and mood with a relative sparing of memory orientation and language. A person suffering this illness may show social and personal neglect,

a lack of judgement and disinhibition. The change in mood may be one of euphoria and irritability or on the other hand depression. Anti-social behaviours are quite common and have been reported in up to 50% of sufferers.

Fronto-temporal dementia is an illness which develops most commonly in a person in their 60s and it accounts for 25% of all dementias developing before the age of 65. There appears to be a strong genetic link to the development of this group of illnesses, both familial and sporadic cases.

Dementia with Lewy Bodies

Dementia with Lewy bodies is a dementia syndrome which includes fluctuating mental abilities, Parkinsonism and visual hallucinations. Most sufferers develop symptoms in late life between the ages of 60 and 90 years. The onset of the illness is usually insidious with declining cognitive function showing deficits of memory and language. To make the diagnosis, dementia must occur before the onset of Parkinsonism and this distinguishes dementia with Lewy bodies from Parkinson's disease dementia where the Parkinson's disease pre-exists the development of dementia. Fluctuation in symptoms refers to a variation in alertness, cognitive function and ability to care for oneself. These fluctuations have been found in 80% of sufferers and are sometimes very rapid.

Visual hallucinations occur in almost half of all sufferers of dementia with Lewy bodies. These are typically vivid hallucinations of animals or people. Sleep disorder is also a frequent symptom.

Korsakoff's syndrome

Korsakoff's syndrome is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory. People usually retain skills that they acquired before developing the disorder, so they are often able to manage with appropriate support but about a quarter make no recovery and may need long term care. Korsakoff's is likely to continue to progress if the person continues to drink heavily and has poor nutrition.

Those affected tend to be men between the ages of 45 and 65 with a long history of alcohol abuse, though it is possible to have Korsakoff's at an older or a younger age. Women can also be affected. They tend to develop Korsakoff's at a slightly younger age than men as they appear to be more vulnerable to the impact of alcohol. It has been suggested that whereas it may take around 20 years for a man to develop Korsakoff's syndrome, it may take about half that time for a woman. It is not yet clear why some heavy drinkers develop Korsakoff's syndrome and others do not, although there is some evidence that it may relate to diet.

Dementia plus

Many older people experience dementia as part of a complex mix of physical and mental illnesses, due primarily to the association with ageing. There is anecdotal evidence that it is often masked as it is not the primary diagnosis. Conversely some people are diagnosed with dementia when further investigation reveals that their confusion and delirium is caused by a treatable physical condition, such as a urinary tract infection.

It is also common for the first signs of any problem to the health and social care system are when a carer presents with stress and other symptoms of breakdown. It is important to identify the underlying causes at this stage and provide assistance if an expensive crisis such as hospital admission or care home placement is to be delayed or avoided.

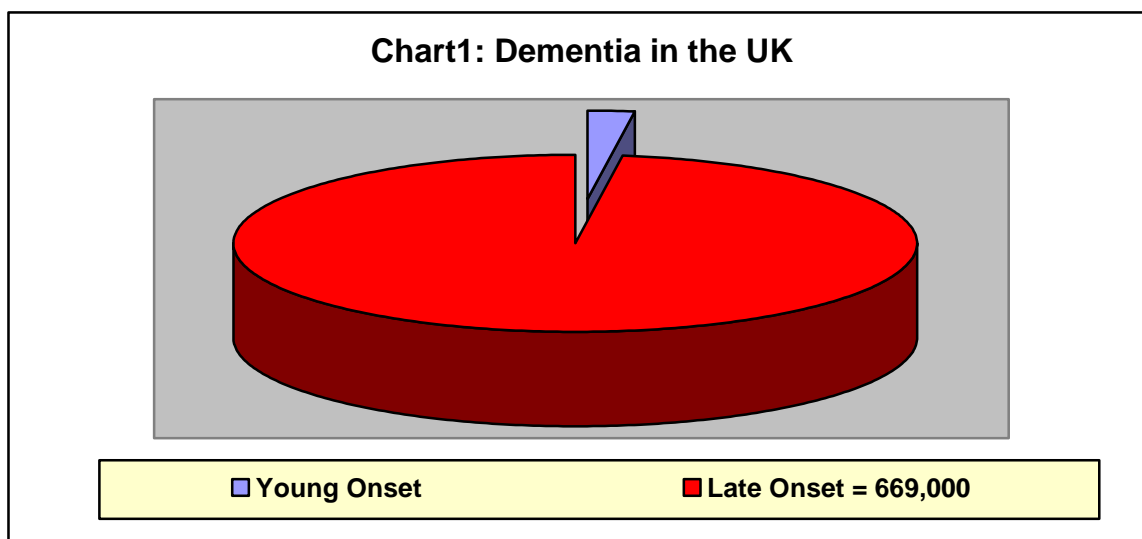
People with longstanding conditions are living longer and are also more likely to develop some form of dementia at a younger age. For example, Continuing Healthcare assessors are experiencing problems in finding services that are able to provide for people with learning disabilities and dementia. Current drugs being prescribed for people with HIV, who are now living for many years with the disease, are known to lead to dementia developing at a younger age.

3: The current picture and future trends – nationally and in Manchester

The National Picture

The consensus of national research ⁹ estimates that over **680,000 people** in the UK currently have dementia. Nearly two thirds of these people live in the community; a third in residential care or nursing homes

Although it can affect people at any age, it is most common in older people and becomes more prevalent with increasing age. Just over 15,000 people are thought to have young-onset dementia (onset before the age of 65), in comparison with nearly 669,000 who have developed it later in life.



The likelihood of experiencing dementia doubles every 5 years in later life. By the age of 95, one in three people are affected.

Some ethnic groups have higher rates of vascular dementia than the population as a whole. This is due to the higher rates of heart disease and stroke in some populations. It is estimated that there are 11,500 people from BME groups with dementia in the UK.

The economic consequences are huge. *The UK Inquiry into Mental Health and Well-being in Later Life* ¹⁰ found that dementia costs the health and social care economy £4bn a year – more than cancer, heart disease and stroke combined.

It has recently been predicted ¹¹ that, by 2025, **one million people** in the UK will be affected. This forecast is based on two main assumptions – the disease

⁹ Summarised and refreshed in *Dementia UK*, Alzheimer's Society. February 2007 and detailed in Appendix 1 of this document.

¹⁰ *Improving Services and Support for Older People with Mental Health Problems*. Age Concern. August 2007

is likely to continue to occur in the population at the same rate as it does now (no “cure” in sight) and that the 65+ population will grow faster than the population as a whole. Despite recent announcements about possible new drug therapies, it is clear that, even if proved successful, these are some years off. They should not be used as an excuse to delay action.

Dementia in Manchester - the local picture and predictions for the future

To plan for the future of dementia services in the City, we need to know how many Manchester people have dementia now, the severity of their illness and what we can predict about future trends. This is a complex task. The Joint Health Unit did an exercise with the University of Manchester to inform the recent review of older people’s mental health services (Cordis Bright)¹² and their findings have been used, with additional comments.

Population Baselines & Projections

Because dementia prevalence is so crucially connected to age, being able to predict future population trends and age profiles are key to developing a forward-looking dementia strategy for Manchester. After a long fall from its 1931 height of 766,000, Manchester’s population decline “bottomed out” at 416,400 in 1999 and currently stands at 452,000¹³. This upward trend is due to continue.

Projections of how many people will live in the City in the future are available for Manchester’s resident population up to 2029¹⁴. These show the population of Manchester growing at more than twice the rate for England as a whole. However most of this increase is in the population under 65. However PCT figures are based on *registered* populations. The Joint Health Unit has also developed projections for the overall 65+ group, based on *relevant* population, for a number of years. (See Appendix 2 for a note on different population groups.

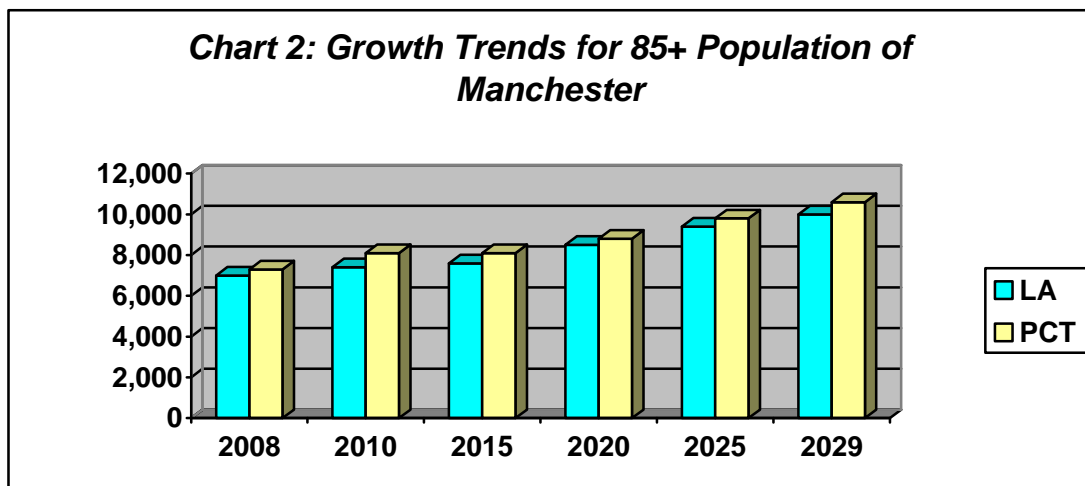
Generally, the overall 65+ population is projected to be stable for the next few years, followed by a steady upward trend up to 2029 – with an overall growth of just under 20% between 2006 and 2029. More significantly, the 85+ population has shown strong growth in recent years, and is predicted to continue to “outperform” the overall 65+ population, growing by over 51% in the same period. This is illustrated in Chart 2, showing that instances of dementia will increase. .

¹¹ *Dementia UK*, Alzheimer’s Society. February 2007

¹² Review and Needs Assessment – Older People’s Mental Health. November 2008

¹³ 2006 mid-year estimates. ONS. August 2007

¹⁴ 2004 Revised Sub-national population projections. Planning Studies. Manchester City Council



However, great care has to be taken in the interpretation of these projections as they are based solely on past trends. They are not predictions or forecasts; they merely project what will happen if past trends continue at the same rate.

It may be useful to also include an element of prediction here, given what we know about the changing situation in Manchester. For obvious reasons this will be very speculative, but it is argued that predictive elements can be of greater significance than those arising from projections.

There are a number of factors that could impact on the projections given, and, whilst it is difficult to quantify these with any accuracy, it is suggested that any projections given be considered as a minimum, with numbers likely to be more.

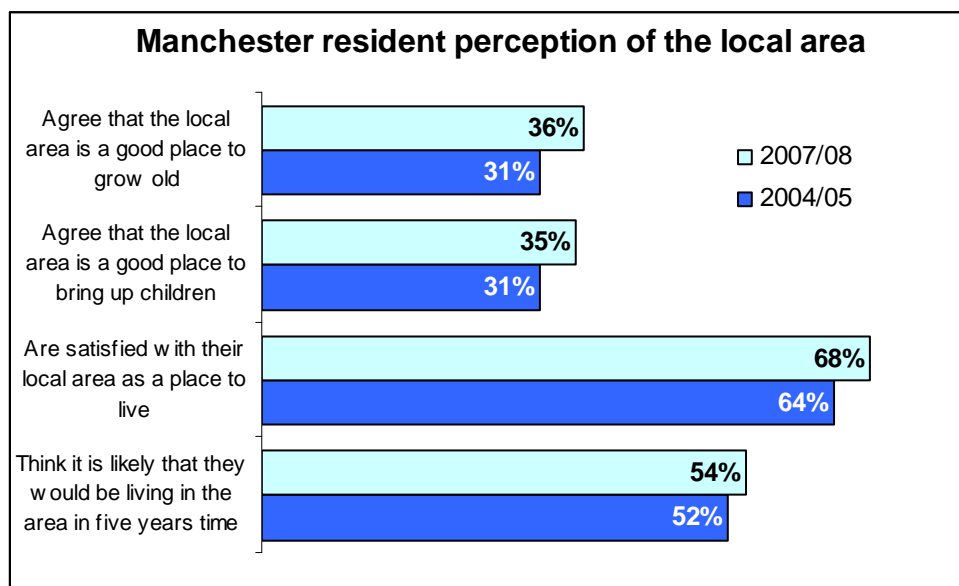
The issues that are likely to be important are:

- 1: Whether more people choose to age in place in Manchester will change the age profile of the City.

Apart from the corporate objectives that this should occur there is some evidence that this may be occurring more than in the recent past. (See Chart 3)

There is no doubt that a change in the age profile of Manchester would have a far greater impact on future levels of dementia than the ONS population projections.

Chart 3



Source: Manchester City Council Quality of Life Surveys 2004/05 and 2007/08.

2: Levels of deprivation are also an issue. As part of the work undertaken by the Joint Health Unit referred to above Dr. Jane Byrne, Senior Lecturer at the University of Manchester, comments that there is increasing evidence of a link between deprivation and dementia prevalence. Manchester is the third most deprived local authority in England and there are polarised patterns of deprivation within the city.

3: The socio-economic profile of older people in Manchester. If older people living in Manchester have higher levels of poor health and social isolation than older people nationally this could impact on the actual rates of dementia. Consequently any changes to the socio-economic profile could affect the rates of dementia more than the population projections.

4: Diversity is another potential factor as there is evidence that some BME populations have higher incidence of certain types of dementia.

Building a Local Picture of Dementia

The Joint Health Unit estimates that the number of cases of dementia in Manchester will increase by around 300 (about 6%) between 2008 and 2016. The exact numbers are 65+ cases increasing from 4510 to 4746, and young onset from 92 to 101, giving a total of **4,847** cases in 2016. (Young onset dementia is shown as increasing by nearly 13%. However, as discussed above, this is due to the much greater projected increase in the younger population.).

The following are extracted from tables produced by the JHU.

Projected estimate of the number of people in Manchester with dementia 2006-2016
Based on Expert Delphi Consensus on the prevalence of dementia (Dementia UK)

Year	Males			Females			Persons		
	Young onset (30-64 years)	Late onset (> 65 years)		Young onset (30-64 years)	Late onset (> 65 years)		Young onset (30-64 years)	Late onset (> 65 years)	
		All residents	Residents of care homes		All residents	Residents of care homes		All residents	Residents of care homes
2008	54	1,518	610	38	2,979	1,447	92	4,510	2,030
2012	58	1,635	649	40	2,897	1,411	97	4,589	2,070
2016	60	1,775	702	41	2,925	1,427	101	4,746	2,145

Source: *Dementia UK* © Alzheimer's Society 2007; 2001 Census Standard Table S001 © ONS. Crown Copyright

Patterns of use of Care Homes given above are based on current usage. Changing services may alter these, giving more opportunities for people to stay supported at home for longer.

The most recent locally generated data on dementia (the Dementia Register kept by all GP practices in the Manchester Primary Care Trust area) records **1,816**¹⁵ people with a diagnosis of dementia on local GP lists – about 0.34% of the registered population. However, this is not a reliable guide to how many people actually experience the disease, as it is frequently undiagnosed in its mild or moderate forms.

Locally, we know from a recent survey¹⁶, that organic mental health is a key trigger leading to older people accessing adult social care services (11.7%) and represents an underlying trigger in 31.3% of cases. If these figures are extrapolated to the total older people's assessed population for a year, they give 387 presentations where organic mental health is the presenting issue and 1034 cases where it would be an underlying issue. There is also the continuing issue of 'resident' and 'registered' populations used as a base.

The prevalence rates suggested below are based on separate models for early and late onset dementia published by Dementia UK¹⁷. The rationale behind the figures given is detailed in Appendix 3, which gives more information.

A summary of the figures in the appendix show that by 2016 there are projected to be **4,847** people with dementia in Manchester – 4,746 with late onset and 101 with young onset.

¹⁵ 2006/07 results for Quality & Outcome Framework

¹⁶ From a recent case file analysis conducted for Manchester's Prevention/ Early Intervention Strategy

¹⁷ *Dementia UK*, Alzheimer's Society. February 2007. See Appendix 1 for the model.

More crucial than these overall numbers is the proportion that is likely to experience **severe cognitive and/or physical impairment** and need intensive health and social care support. This will have significant consequences for dementia planning, including the demand for specialist nursing care beds. It is possible to predict a growth in these numbers from approximately 1,350 of the resident population in 2006 up to, **1407** by 2015 – equivalent to an increase of 15 cases per year.

Table E: Prevalence rates and forecast numbers for mild, moderate & severe late-onset dementia in Manchester up to 2015

Year		Mild	Moderate	Severe	Total
2008	LA	688	1982	1376	4046
	PCT	746	2151	1492	4389
2010	LA	687	1981	1374	4042
	PCT	746	2151	1492	4389
2015	LA	704	2028	1407	4139
	PCT	738	2126	1475	4339

The above total figures differ from those given earlier. This is because a different model was used.

Summary

- Numbers of people with dementia in Manchester are projected to rise by 6% by 2016, to 4847 people. 4746 will be late onset, and 101 early onset.
- It is predicted that this is an underestimation.
- About 1,500 of these people will have the most severe form of the illness.

4: Current services and resources

From the figures given above we can see that the numbers of people with dementia in Manchester in 2008 was estimated to be at least 4510, with the numbers with the severe form of the disease being about 1376. Although much of the provision given below is excellent, it is clear that there are not enough services to meet the needs of these people at this time, and it is clear that demand will grow.

Provision is 55 in-patients hospital beds, 20 beds at Monet Lodge Independent Hospital, 292 EMI beds in nursing or residential homes, 893 people on Community Mental Health Teams for Older People's (CMHTOPs) caseloads (not all dementia sufferers), 10 extra care housing places, 40 day hospital places and 65 specialist day care places. The situation is complicated by the fact that each day care place is used by more than one person a week, but also by the fact that some service users use more than one service.

It has proved impossible to give a definite list of services and resources. Many services provide for older people with functional illness as well as dementia, services do not have distinct staffing, and budgets are configured in different ways. Manchester mental health services still very much reflect the past when there were 3 different authorities.

However it is undoubtedly true that , although there are some excellent services, and some good co-ordination, and that people with dementia in Manchester are better served than in surrounding boroughs, local provision falls far short of demand. The main part of caring is being done by informal carers.

Current provision in Manchester

The key partners in the Manchester health and social care economy for people with dementia are Manchester City Council; Manchester Primary Care Trust; the Manchester Mental Health & Social Care Trust; specialist housing associations; voluntary organisations such as the Alzheimer's Society and Age Concern; private sector providers of residential, nursing and hospital care; informal carers.

It has proved impossible to carry out a full audit of services for people with dementia. Most specialist services provide for older people with functional illness as well as organic, many people with dementia receive general services such as day care, home care or residential care, and many cases of dementia are not recorded as it is not the primary condition. For these and other reasons the following is far from being a total list of all the services used by people with dementia and their costs.

Costings given are to the Joint Commissioning Team (JCT) in 2008/09 unless otherwise specified.

Community Mental Health Teams for Older People

There are six local teams (2 in each locality), run by the Manchester Mental Health & Social Care Trust (MMHSCT) who provide multi-disciplinary assessment, treatment care co-ordination and support to people over 65 with organic and functional mental illnesses whose needs are complex and their carers. Each team has a manager and access to psychology, psychiatry, occupational therapy, nursing, social work and support workers. The teams are not exclusively for people with dementia but a high proportion of service users have cognitive impairment of varying degrees. A snapshot of the caseloads in the autumn of 2008 gave the following information:

South

- 143 on the caseload
- 7.2 CPNs, 2 OTs, 2 support workers, 1 admin, 2 social workers.

Central

- Total CMHT Caseload around 350
 - 6 CPNs, 2 OTs, 1 OT technician, 2 Social workers, 7 support workers, 1 support worker coordinator 2 .6 admin
- (However the situations are not comparable as administration staff do different tasks in different localities).

North

West Sector

- Case load around 200
- 2.0 nurses specialising in dementia/challenging behaviour supported by 2 support workers
- 3 trained nurses specialising in dementia assessment/intervention
- 0.5 nurse memory treatment clinic/carers support groups/carers workshops/post diagnostic counselling for both east and west
- 4 generic CPNs all who see small numbers of people suffering from dementia, particularly where there is multiple diagnosis(currently one post vacant and one part time hours)
- 1 social worker
- 0.5.OT
- 2 support workers provide support to all above nurses
- administrative support

East Sector

- Case load around 200
- 2 .0 nurses specialising in dementia/ challenging behaviour supported by 2 support workers
- 2.0 nurses specialising in dementia assessment /intervention. One provides input to memory treatment clinic 1/2 day per week
- 4 generic CPNs all who see small numbers of dementia sufferers, particularly where there is a multiple diagnosis
- 1 Social worker

- 0.5. OT
- 2 support workers provide support to all above nurses
- administrative support

Costings: £6,394,000

(However this figure is for all OPCMHT work, some of this is with functional illness. It excludes psychiatry and psychology costs as those are in separate budgets – but those also include functional illness).

Dementia Treatment Clinics

These are provided in each of the 3 districts of the Manchester Mental Health & Social Care Trust (MMHSCT) area, and offer assessment monitoring effectiveness and side effects of dementia treatment, and medication. Most input is from nursing staff that are part of the Community Mental Health Teams. There is psychiatrist input to all clinics, and psychology assistant input in North.

South

- see Memory Clinic

Central

- Caseload 130
- 0.8 WTE B7 Nurse

North

- 1/2 day per week also serves Middleton residents
- carer support group
- 6 week carer workshops
- post diagnostic counselling group.
- 0.5 nurse memory treatment clinic/carers support groups/carers workshops/post diagnostic counselling for both east and west. All resourced from North CMHTs

Memory Clinic

This is a city-wide service of the Manchester Mental Health & Social Care Trust (MMHSCT), based in the South District Dementia Treatment Clinic:

- assessment for and treatment of memory problems
- post diagnostic support group
- 1 manager
- 0.6 clinical psychologist
- p/t administration .
- RMN input from South CMHT for South service users on memory treatment

Costing: £111,000

Psychiatric Outpatient Clinics

Clinics are available in North, Central and South Manchester. Psychiatrists accept referrals from GPs and assess, diagnose and if appropriate treat many people with dementia.

Clinical Psychology

Input to the CMHTs is available in North, Central and south, although staffing levels vary across the city. Staff offer a range of services including specialist neuropsychological assessment, post diagnostic support, memory rehabilitation, behavioural interventions, and family therapy and CBT interventions for carers.

Staff are also involved in research and audit projects concerning dementia care, and in the training and supervision of others.

Young Onset Dementia Service

This is a City-wide service, provided by MMHSCT. It offers day assessment and a treatment unit for people who develop dementia early in life and support for their carers.

- Caseload 42 clients and their carers
- 1 x Service manager; 2.4. qualified staff (currently 2 x nurses and part time care manager – post vacant). 4.4 carer staff; 0.8 team secretary
- Unfunded input from psychology (0.2 f.t.e.) and psychiatry.

Cost: £306,000

Day Care, Respite and Assessment Beds

The MMHSCT also provides a Day Assessment Treatment Unit at Hall Lane Day Hospital and at the Phoenix Assessment Unit – both in South Manchester. Both units take people with functional and organic illness on separate days

Hall Lane

- 20 places- 30 on caseload
- Staffing: 1 manager, 1 assistant manager, 2 part time staff nurses, 3 part time nursing assistants, 1 admin.
- About one third of the places are currently occupied by people with dementia (information provided by Dr. Lennon)

Phoenix

- 20 places; 40 on caseload
- Staffing 1 manager, 3 staff nurses, 2 part time nursing assistants, 1 part time admin.

- None of the places currently occupied by people with dementia (information provided by Dr. Lennon)

Cost: £179,640

Age Concern has two day centre services across the city in Miles Platting and Gorton which specialise in older people with mental health problems. There are 65 places a day available from Monday –Friday. A range of services are available at these sites to older people, such as counselling for those experiencing mental health problems, information, advice and support.

Cost £217,500

However a recent audit has found that there is little difference between the customers of these services and older people referred to general day care centres.

Admiral Nurses

Three Admiral Nurses, one for each PCT district, operate in the City as part of the MMHSCT. The service is funded by the Joint Commissioning Team for Mental Health. In the first 10 months of 2007 the service received 182 referrals. They also help run the memory cafes.

Cost to JCT £179,483

Inpatient Hospital Beds

There are 3 wards, run by the Manchester Mental Health & Social Care Trust (MMHSCT):

North

Cedar Ward. 20 beds for people over 65 with organic and functional mental illnesses. 24 hr care, assessment and treatment.

Central

Cedar Ward. 12 beds for people over 65 with organic mental illnesses. 24 hr care, assessment and treatment

South

Cavendish Ward. 23 beds for people over 65 with organic and functional mental illnesses. 24 hr care, assessment and treatment.

(It is estimated that less than half the beds in North and South are occupied by people with dementia at any one time).

Monet Lodge is a 20 bed **independent hospital** in Withington for older people with dementia and associated challenging behaviour who also meet continuing care criteria, or are detained under the Mental Health Act. It is a city-wide service and is currently provided by Making Space.

Cost £968,000 p.a.

Residential & Nursing Care

There are currently 305 elderly mental illness (EMI) beds for older people in Manchester, at 8 facilities across the City, made up of 193 nursing beds and 112 residential beds out of a total of 3250 (out of which Adult Social Care purchases 1724). There is 1 EMI nursing home which will not take people whose primary diagnosis is dementia. (See Table F below for detailed list.)

According to the Wanless Report¹⁸, in 43% of cases mental health problems are cited as a reason for older people moving to residential and nursing care. The Alzheimer's Society Report, Home from Home, found that two thirds of care home residents have some form of dementia, and that only 60% of those are in EMI registered beds. The situation in Manchester would suggest an even starker picture, given that only 10% of registered care beds in the city have EMI status

<i>Table F: Elderly Mental Illness (EMI) Beds in Manchester</i>				
<i>Ward</i>	<i>Name of Care Home</i>	<i>Registered EMI Beds</i>		
		Nursing	Residential	Total
Miles Platting & Newton Heath	Averill House	45	3	48
Gorton North	Gorton Parks Nursing Home	30	90	120
Woodhouse Park	Marion Lauder	45	0	45
Cheetham	Nada Residential and Nursing Home	17	11	28
Sharston	Ringway Mews Nursing Home	30	0	30
Ancoats & Clayton	Seymour Rest Home	0	8	8
Chorlton	Conifers Nursing Home	5	0	5
Longsight	Victoria Nursing Home	21	0	21
<i>Totals</i>		<i>193</i>	<i>112</i>	<i>305</i>

Workforce Development and Training

¹⁸ Wanless, Dereck. Securing good care for older people. King's Fund. 2006

Adult Social Care Workforce Development section provides dementia awareness training aimed at all staffing residential and nursing care homes. There is one staff member who co-ordinates this, using mainly Admiral Nurses to deliver the training. However this staff member is responsible for all training to care homes.

“Preventive” Services

Manchester’s Partnership for Older People Projects (POPP) funded a number of community based preventive schemes, designed to address the social exclusion of older people and provide practical, timely support to enable them to take control of their lives and continue to remain independent in their own communities. During the three rounds of funding, a number of dementia-related schemes have been supported:

- The Manchester Admiral Nursing Service has developed a ‘buddying’ scheme to support carers.
- Memories’ and ‘POPP Inn’ Dementia Cafes have been established in Didsbury and Wythenshawe for people with dementia and their carers to relax and meet up with people in similar positions to themselves.
- The Alzheimer’s Society in Manchester also offers a befriending service to dementia sufferers who are ready for discharge from hospital back to their own homes

Mainstream funding has been obtained to continue the above services until September 2009.

Costs to ASC and PCT £70,270

Supported Accommodation

The Supporting People (SP) programme fund a number of community-based supported accommodation services:

- People First Housing Association run an early intervention project for people with memory loss. The service has a caseload of 35.
- A floating support service for older people with mental ill health is based in the Wythenshawe area. The service is linked to GP surgeries and support workers are assigned to people before they reach crisis point, for example, those with low-level depression. The caseload for this service is 20.

Cost to Supporting People £604,773

Unified Dementia Service

This service is made up of 3 distinct elements that people can combine into flexible care packages. These are outreach services into people’s homes, day

care, and 8 respite beds, all based at the Marion Lauder EMI nursing home to give continuity for service users. There will also be 4 beds for assessment

This is a pilot scheme operating in the Wythenshawe area. It will be closely monitored and evaluated. If successful it is planned to extend it city-wide.

Cost to ASC: £790,000

Extra Care Housing

There is a 10 place extra care housing scheme for older people with memory loss at Shore Green in Baguley.

Cost: ASC £179,060 a year (gross) for 267 care hours a week, including 63 waking night hours. SP support is £60,060

There are also three other sheltered accommodation schemes in the City which specify older people with mental health problems/dementia as a secondary client group (two in Moss Side/Whalley Range; one in Wythenshawe)

Alzheimer's Society

The Manchester branch offers a befriending service. 3 carers' support groups in North, Central and South, and a dementia outreach service.

Cost: £22,608 to JCT, £40,000 from ASC (Carers Grant)

Supporting Health Programme

The Public Health Development Programme, in partnership with MMHSCT supports people with serious mental health problems to improve their physical health. This programme has been recently extended to people with dementia and their carers for an initial 2 year period subject to evaluation.

Cost: £100,000

5: What you told us

Between April and August 2008 the Dementia Strategy Working Group developed service user/carer and staff questionnaires and both were widely promoted. They were available in a paper format and on-line. Copies of the full analysis are available.

In addition to carrying out the surveys, members of the working group visited Memory Clinics, Memory cafes, carers' groups and a number of care homes, speaking to service users and carers and noting their views.

237 returned the forms: 90 service users and carers and 147 staff.

Please note that the numbers (and percentages) for individual questions vary as some people did not answer every question.

People with dementia and carers

There were 90 people in this category, 10 were people with dementia and 80 were carers:-

- 41 (46%) were 65+. However, only 3 were 85+ (3%)
- 60 (67%) were White British
- 36 (40%) had experienced dementia for over 4 yrs, 39 (43%) for 1-3 yrs
- 35 (40%) had been to the GP less than six months after first worries
- 35 (40%) received a diagnosis within 6 months of going to the GP
- 58 (75%) were Manchester residents, with no locality bias
- 5 people (7%) had to wait over 2 years for a diagnosis

When asked what services would have helped, those respondents echoed the priorities in the Government's National Strategy:-

- faster diagnosis
- more information, at all stages of the illness
- more support
- consistent support

"A regular, reliable support worker who would understand, and stand by me when trying to help a very difficult individual."

There was much praise for individual services, especially for Admiral Nurses:-
"My Admiral Nurse was always there for us. I call her an angel – she has been wonderful". "Having the Admiral Nurse with me for support at the time of X's death and after was invaluable, as was being able to know that she would be there for me at times of crisis. This helped me to continue caring for him at home as he wished".

"Community podiatry services..... were excellent".

"The care and attention my wife has had from all sectors were wonderful and I thank them from the bottom of my heart".

"I get wonderful support from the drop-in cafes – always come away feeling better".

"The drop-in cafes are good – meeting people with the same problem helps. We still meet friends we met at the Memory Clinic and we help each other, even if it is just talking – we need to meet other people in the same situation".

"R's journey regarding his dementia has been excellent. From his initial diagnosis after stroke and support from dementia nurse at Wythenshawe to help from psychiatrists, to carers in home and Admiral nurses. I could not have asked for more as there was continuity of care".

However, there were far more comments about lack of information and services, staff not understanding how to work with people with dementia, and being left to cope alone.

"There was a lack of information particularly when the illness was first diagnosed and this has continued..."

"Lack of sufficient specialised district community nursing services and use of other agencies in lieu of adequate care services".

"There needs to be more help available to those people in the mild/moderate stages of Alzheimer's who are vulnerable, but unfortunately do not meet the criteria for packages provided by Social Services".

"The first stages of the illness are very frightening. We should have been helped to make decisions and strategies and try and slow down the process."

"I was struggling for years with no help."

"I think people just tend to say 'Oh its dementia' as if there is nothing more that can be done and I feel that in a lot of cases the family are left to struggle alone".

"Poor organisation of carers at times, different hygiene standards and poor communication skills, lack of knowledge with reference to strokes, paralysis and dementia".

The most striking area of agreement was the 91% of respondents who wanted specific dementia services at all stages of the illness from diagnosis onwards. It is unclear whether this would be a lower proportion if generic services improved in quality and staff were trained in dementia awareness. However, carers spoke about their embarrassment when the cared for acted 'inappropriately' in company, and information from other sources report a growing number of complaints from people who have not got dementia at their distress in sharing services with people whose behaviour is quite disturbed. This may well be a factor for the 83% of staff who also wanted separate services from diagnosis on.

"I have not been diagnosed with dementia, though I am very forgetful. I am 95 years old and living in care because I am physically frail. When I first moved to this care home four years ago people living here with dementia integrated well with other residents. Now people with advanced dementia in the home are in the majority. I have no-one I can relate to, except the staff that are too busy to chat... I feel very isolated in my own home because I cannot communicate with other residents".

NHS, Social Care and Voluntary Sector staff

147 people filled in the questionnaire, with 124 completing all the sections.

They came from the following areas:-

▪ MMHSCT – Community	33
▪ MMHSCT – Hospital	18
▪ MMHSCT – City-wide	6
▪ General Practice	25
▪ Voluntary Sector	21
▪ NHS Manchester	15
▪ Manchester Community Health	13
▪ Independent Care Provider	8
▪ Adult Social Care	7
▪ Acute Hospital NHS Trust	3
▪ Housing	1
▪ Other	6

In broad terms the views of the staff were similar to those of the services users and carers, and both shared the priorities identified in the National Dementia Strategy.

For example staff who worked directly with dementia sufferers were asked what services could be available to help them (123 answered);

	%	No.
▪ More help in a crisis	62	76
▪ More training	60	74
▪ Practical advice and guidance	55	68
▪ More staff	49	60
▪ More assistive technology	30-	37

The services they found most useful were many and various, and across sectors. As with service users and carers Admiral Nurses, the Memory Clinic and Alzheimer's Society were praised, as were a variety of specialist and non-specialist services: Hall Lane, EDIT and SPRITE teams, MRI One Stop Clinic, St. Joseph's Care Group, Speech Therapists ("trained to work with people with dementia") and the Equipment and Adaptations Service and many more.

However, there were many gaps, both in terms of more of services and a wider variety:

"More befriending type services".

"Good care agencies who spend a good amount of time with clients".

"Appropriate day care and respite facilities".

"Better training"...." for staff in residential homes." "for health and social care staff" "..for carers".

"lack of..." respite beds, appropriate EMI placements, challenging behaviour placements, home carers that have training in dementia care

Major gaps were identified for people under-65 and for people with Down's syndrome and dementia, most of whom are also young onset.

The people visited by the working group members reflected the findings from the survey, with emphasis on the need for continuity of care, with one main member of staff being responsible for co-ordinating communications and services. It was also apparent that the service users and carers talked to were less enthusiastic than professionals about the use of new technology, fearing that it would be used to replace regular, consistent, human contact

A G.P. in South Manchester shared a letter from the relatives of a patient who had experienced a lack of co-ordinated support, with missed visits, no communication from services and little understanding of dementia from care staff. The patient's care improved at the end of her life when she moved to stay with her daughter in another borough.

The Cordis Bright review conducted for the JCT in the autumn of 2008 found similar views and gaps. Their main recommendation is to increase dementia services throughout the city.

6: Where we are against the National Strategy

This table gives the objectives from the National Dementia Strategy, with what we have in place in Manchester towards achieving them and some suggested future actions

No.	Objective	What we have in Manchester	What we could do
1	<p>Improving public and professional awareness and understanding of dementia.</p> <p>Address the stigma attached and encourage people to seek early help.</p>	<p>Local Alzheimer's Society plays an active role in all national campaigns.</p> <p>Production of a local strategy has raised the profile of the disease in health and social care.</p> <p>ASC provides dementia awareness training to staff and care home providers.</p>	<p>Increase local awareness of the national campaign e.g. in Libraries.</p> <p>Extend training to include all staff who work with older people.</p> <p>Campaign in general hospitals to improve awareness</p>
2.	<p>Good quality early diagnosis and intervention for all.</p> <p>Access to a pathway of care that gives rapid assessment and treatment, care and support as needed</p>	<p>Central Manchester have a 'one-stop shop' for people referred for dementia screening where all the tests are co-ordinated for the same visit.</p> <p>People with a possible diagnosis of a dementia are referred to CMHTs and/or the Memory clinic and other services. However it is felt that for many diagnosis is delayed because of failure to refer early or long waiting time to complete assessments</p>	<p>Remind GPs of the Dementia protocol and the need for quick referral to specialist assessment services. This could be done in conjunction with the annual Alzheimer's Society mail-out to all GPs.</p> <p>Improve the pathways when referred to the specialist service.</p> <p>Reduce waiting times by increasing the service capacity.</p> <p>Increase the services available to provide care and support</p>
3.	<p>Good quality information for those with diagnosed</p>	<p>Good quality information is available but it is</p>	<p>Test the Information Prescriptions with customers, carers,</p>

	dementia and their carers, both at diagnosis and throughout the course of the illness	<p>not always easy to access.</p> <p>ASC have produced an Information Prescription for Dementia.</p> <p>There is no routine provision of information about dementia or the services available across all services which provide care for people with dementia and their carers.</p>	and other stakeholders to ensure they meet needs
4.	<p>Enabling easy access to care, support and advice following diagnosis.</p> <p>The NDS proposes dementia advisers.</p>	<p>There are 3 Admiral Nurses who fulfil a version of this role. However, the Alzheimer's Society estimates that, if advisers had a caseload of 200 each, we would need 14 in Manchester.</p> <p>Support and advice is also offered by CMHTs and the Alzheimer's Society</p>	<p>The dementia adviser role is being tested in half the Demonstrator sites. We should wait until the results of these are known and more guidance has been issued.</p> <p>A joint care pathway should be developed and the capacity of the CMHTs increased</p>
5.	Development of structured support and learning networks	<ul style="list-style-type: none"> • 3 Carers' Support Groups • 4 Memory cafes • Post-diagnostic support group • SONAS group (speech and language therapy) • Befriender service • 3 Admiral Nurses 	<p>Submit a bid to be a demonstrator site for the peer support strand of the NDS to expand and co-ordinate support across the city</p> <p>Do this work even if government finance is not obtained</p> <p>Establish financial security for the existing services, many of whom are short-term funded or provided from diminishing charitable resources</p>

6.	<p>Improved community personal support services. Provision of a range of flexible and reliable services.</p>	<p>A unified dementia project is being piloted in the Wythenshawe area. To date it is proving popular, especially with carers.</p> <p>The Alzheimer's Society is piloting a specialist home care service from the summer of 2009.</p>	<p>If the evaluation of the pilots demonstrate affordable success look to roll out the models across the city.</p> <p>ASC to keep cases open on their files to enable ongoing support and quick responses through an illness whose symptoms can change constantly</p>
7.	<p>Implementing the Carers Strategy. Carers should have an agreed care plan with personalised breaks.</p>	<p>Manchester has a Carers' Centre and a Carers' Forum and carers are actively involved in distributing the Carers Grant and other aspects of the Strategy.</p> <p>ASC is prioritising carers' assessments and offers of Individual Budgets to carers.</p> <p>Both ASC and the Alzheimer's Society provide respite breaks.</p> <p>In 2009/10 ASC is introducing a higher band of support for people caring for people with dementia.</p>	<p>Be more pro-active in linking the Dementia Strategy work with the Carers Strategy.</p> <p>Actively identify and seek out informal carers of people with dementia so that support can be offered.</p>
8.	<p>Improved quality of care for people with dementia in general hospitals. Identify a lead for dementia in each hospital and commission specialist liaison teams.</p>	<p>UHSM has a Nurse Educator post, which also supports carers and dementia sufferers and provides more general training.</p> <p>There are old age psychiatric liaison services at all 3 acute Hospital Trusts. However, these are limited and unfunded.</p>	<p>Commissioners should require acute Trusts to put in place specialist psychiatric liaison teams as described in the NDS.</p>

		This area is recognised as a big gap. There are no acute Trust leads.	
9.	Improved intermediate care for people with dementia	<p>A recent review of intermediate care and re-ablement services found that over 30% of customers in the north and central districts had some form of mental illness in addition to the physical reason they were in the service, most of it dementia. This contradicted the prevalent view that they were excluded from such services.</p> <p>However people working in mental health services still feel that people they refer to intermediate care are excluded.</p>	<p>Standardise the monitoring of people with mental health problems using re-ablement services.</p> <p>Ensure that re-ablement services are designed to meet the needs of people with dementia.</p>
10.	Considering the potential for housing support, housing-related support and telecare to support people with dementia and their carers.	<p>The Shore Green extra care housing scheme is nationally recognised as a success.</p> <p>Supporting People money finances 2 floating housing support services.</p> <p>ASC is promoting the installation of assistive technology to older people.</p> <p>NHS Manchester is investigating the use of telemedicine.</p>	<p>Build on the success of Shore Green to provide dementia specific extra care schemes in the north and central districts of the city.</p> <p>Institute a specific programme to market suitable telecare products to carers of people with dementia.</p>
11.	Living well with dementia in care homes. A dementia champion in each home,	In 2007 ASC developed an additional specification for specialist Emi homes, and	<p>Require homes to nominate a dementia lead.</p> <p>Extend the UHSM</p>

	specialist in-reach services and improved inspection	<p>announced a weekly premium for all homers that met the criteria. For 2009/10 this stands at £20.</p> <p>The EDIT team offers advice and support to homes in North Manchester.</p> <p>Training in dealing with dementia is available to the staff of all care homes (but the take-up is variable)</p>	<p>nursing home team to include mental health professionals so that it can assess and manage the needs of people with dementia and other mental health problems in care homes.</p> <p>Compare this model with the EDIT team and look to roll out the best model across the city.</p> <p>Ensure that homes have access to allied professionals such as dentists and opticians who are trained to work with people with dementia.</p> <p>Review the training on offer to ensure that it is fit for purpose.</p>
12.	Improved end of life care for people with dementia	<p>MMHSCT hospital wards make special provision for end of life care.</p> <p>Work is ongoing with NHS Manchester and ASC to ensure that the needs of people with dementia are taken into account in the End of Life care strategy</p> <p>ASC is developing a specialist home care service for palliative care</p>	<p>Ensure that people's wishes concerning their end of life care are ascertained early on.</p> <p>Develop a joint end of life care pathway with trigger points for people with dementia.</p>
13.	An informed and effective workforce for people with dementia. Effective basic training and continuous professional and	<p>It is recognised that training in dementia forms a very small part of basic training in both health and social care.</p>	<p>Work with educational institutions and training sections to ensure that dementia issues are included in all basic training and that regular updates are</p>

	vocational development.		given to all staff. Develop specific training for those working directly with people with dementia.
14.	A joint commissioning strategy for dementia.	This strategy has been produced by a working group including representatives of NHS Manchester, the Mental Health Trust, Adult Social Care, the Carer's Forum, the Alzheimer's Society and a GPSI	Manchester City Council and NHS Manchester agree to prioritise actions from these recommendations The working group is reconfigured to draw up an action plan and put it into effect The work of the group to feed into future commissioning strategies.
Objectives 15-17 , dealing with assessment and regulation of services, research evidence and regional support, are the remit of national and regional bodies.			

7: Gaps

In Chapter 3 we brought together local and national evidence to try and identify current and future trends for dementia in the City. We established a 2008 benchmark of just over 4,000 residents likely to be experiencing late-onset dementia now and built our projection of a 6% increase by 2016 on anticipated demographic changes and accepted dementia prevalence models.

In addition there are 92 people with young onset disease. Figures are higher for the PCT registered population.

These figures are based on the best available evidence. However, for a variety of reasons we feel that this projection is likely to be an under-estimate. There is no reason to believe that Manchester differs from the rest of the country in there being a substantial number of dementia sufferers who are not known to services. It is also predicted that the number of older people living in the City is going to increase by a greater amount than population projections show.

Overall numbers are of little use on their own in identifying future resource and service requirements. A key feature of our modelling has been the identification of the proportion of people likely to be experiencing mild, moderate or severe symptoms. The model we have used¹⁹ classifies 55.4% as having 'mild' dementia, needing little or no care. A further 32.1%, with 'moderate symptoms, are likely to need some care every day. Most significantly 12.5% will need constant care or supervision. By 2015 this will apply to about 1440 people, with more than 2000 more needing some daily care.

Given the predicted rising demand in both overall numbers and in severity of the condition, there is a need for more of the existing services. Admiral Nurses were mentioned by many respondents, but people would also like more memory clinics, more memory cafes, and far more specialist services: home care, day care, extra care housing, residential and nursing care, and far more support for carers.

There are clear areas where there is no provision at present, notably day care and residential care for people with young onset disease. There are no specialist BME services, and there is a small, but growing, need for more specialised services for people with Down's syndrome who have also developed dementia.

There is a lack of specialist dementia training in most health and social care disciplines, and little training in the detail of how to care for people with dementia. There is a lack of old age psychiatric liaison in acute hospitals. There is no clear joint care pathway.

¹⁹ Dementia UK, Alzheimer's Society, February 2007

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8: Recommendations

These have been taken from the evidence presented in the report, particularly the comparison of the situation in Manchester with regard to the objectives in the National Strategy in Chapter 6. They are that:-

1. Adult Social care and NHS Manchester receive this Strategy and prioritise the actions to be taken. A Strategy Implementation Group is established to draw up an action plan and produce a Joint Commissioning Strategy, which will feed into other commissioning strategies.
2. Health and social care commissioners require providers to note the incidence of dementia in people using their services. At the moment it is often not recorded as it is a secondary condition. This results in a lack of any hard information.
3. NHS Manchester requires their acute hospital providers to put in place comprehensive old people's psychiatric liaison services across their hospitals.
4. A clear care pathway will be developed, including GPs, primary and secondary health staff, and social care staff.
5. Dementia awareness training will be extended to all people working with older people, and training be further developed on how to work successfully with people with dementia for care home staff, care staff and others.
6. ASC commissioners require providers of all care homes to nominate a named dementia lead.
7. Following the evaluation of the Unified Dementia Service, and if deemed successful, develop specifications for further specialist community services and put out to tender.
8. Work will continue with RSLs to develop bids for specialist dementia extra care housing schemes.
9. Clear links are established with the work going on around palliative and end of life care, the Dignity Campaign and the Carers' Strategy.
10. Even if the bid to be a Demonstrator Site for peer support is unsuccessful, work to audit and extend existing support projects for both dementia sufferers and their carers is undertaken.

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9: Appendices

Appendix 1	Members of Working Group
Appendix 2	Note on population figures used in the report
Appendix 3	Dementia prevalence models and supporting information to Chapter 3

Appendix 1: Membership of Working Group

Pip Cotterill	Adult Social Care (Chair)
Sean Lennon	Mental Health Trust
Tracey Langley	Joint Commissioning Team
Dunstan Clarke	Adult Social Care
Joy Wales	Mental Health Trust
Sue Clarke	Alzheimer's Society
Lynn Norbury	G.P.S.I
Val Bayliss-Brideaux	NHS Manchester
Simon Katzenellenbogen	Valuing Older People Board
David Williams	Manchester Carers' Forum
Joe McShane	Carer

The above were regular members of the working group. Many other people have contributed to this strategy. We would like to thank them all for their time and trouble. They are:-

Allan Calvert, Sheila Kasavan, Lorraine Burgess, Dudley Ainsworth, Alison Marriott, Alistair Burns, Lesley Gale, Nat O'Brien, Jane Byrne, Fionnuala Stringer, Dave Thompson, Harry Allen, Melanie Brown, Janet Costello, Andrew Welton, Joe Westbrook.

Appendix 2: Note on population figures used in report

PCTs are responsible for commissioning services (including mental health services) on behalf of patients registered with their GP practices, wherever the patients live. These are known as the “registered” population. The city council can only provide services for the population living in the city known as the resident population. However, it is known that the accuracy of registered population can be affected by delays in taking people on and off GP lists and by movements of patients between GP practices in different PCTs. These factors mean that there is often a big difference between the size of the registered and resident populations. This is known as ‘list inflation’. In Manchester, list inflation is estimated to be about 10% (i.e. the registered population is approximately 10% higher than the resident population).

In order to overcome these problems the Department of Health constructs a new population (the ‘relevant population’) which attempts to reconcile the GP registered population of a PCT to the resident population of the equivalent area. The ‘relevant population’ is used as the basis for resource allocation throughout the NHS and it is this population that is used in the main body of this report. However, some information is only available on a resident population base (e.g. estimates of the ethnic population of the city). Where this is the case, the report clearly states that the resident population has been used.’

Appendix 3: Dementia Prevalence Models and supporting information to Chapter 3

Early onset dementia (dementia in people under the age of 65) is relatively rare and, as such, no population based surveys have been carried out into its prevalence in the UK. However, the Alzheimer's Society has produced consensus estimates²⁰, as shown in Table 1 below, which identify what proportion of the population, by age bands and sex, is likely to have this kind of dementia at any one time.

Two models for determining the prevalence of **late-onset** dementia (dementia in people aged 65+) in the UK have been considered here:

- the Expert Delphi Consensus Model, used by the Alzheimer's Society in their recent report "Dementia UK," ;
- the Melzer/Crystal Blue Model²¹

The differences between the models are minor. Both apply to all forms of dementia from mild to severe and agree that the dementia prevalence rate approximately doubles with each five years age group. The Expert Delphi Consensus Model posits an overall 65+ prevalence of 7.3%, compared with a rate of 7.6% for the Melzer/Crystal Blue model. We have used the latter. Both are shown in Table 2 below.

Table 1: Early-Onset Dementia: Consensus Prevalence Model (per 100,000)			
Age (years)	Total per 100,00	Age (years)	Total per 100,00
30-34	9.4	50-54	58.3
35-39	7.7	55-60	136.8
40-44	14.0	60-64	155.7
45-49	30.4		

Table 2: Late-Onset Dementia Models		
	Melzer/Crystal Blue Model	Expert Delphi Consensus Model
Age (years)	%	%
65-69	1.4	1.3
70-74	2.7	2.9
75-79	6.0	5.9
80-84	13.0	12.2
85+	25.0	(85-89) 27.1
90-94	-	28.6
95+	-	32.5

²⁰ Dementia UK, Alzheimer's Society. February 2007.

²¹ Melzer et al. "Alzheimer's Disease and other dementias", Cambridge University Press. 1999, quoted in "Reviewing procurement of nursing home places for older people with mental health needs". Crystal Blue Consulting Ltd. February 2007

Late Onset Dementia - Prevalence

The Expert Delphi Consensus Model, as used by Dementia UK, estimates the prevalence of late onset dementia for different age bands and by gender.

Age	All Persons %	Male %	Female %
65 - 69	1.3	1.5	1.0
70 - 74	2.9	3.1	2.4
75 - 79	5.9	5.1	6.5
80 - 84	12.2	10.2	13.3
85 - 89	20.3	16.7	22.2
90 - 94	28.6	27.7	29.6
95 +	32.5	30.0	34.4

Source: Dementia UK Table 2.2 (Chapter 2 "The Expert Delphi Consensus on the prevalence of dementia in the UK") © Alzheimer's Society 2007

ONS mid year estimates and population projections that are applied to these prevalence rates do not give full information about those aged 85 plus. Mid year estimates have population estimates in five year bands with the top two bands being 85 – 89 and 90 plus. Population projections have population estimates in five year bands with the top two bands being 80 – 84 and 85 plus. Mid year estimates are split by gender but population projections are not.

For this reason the prevalence rate in the 85 plus age group has been averaged in the Manchester modelled prevalence rate calculations.

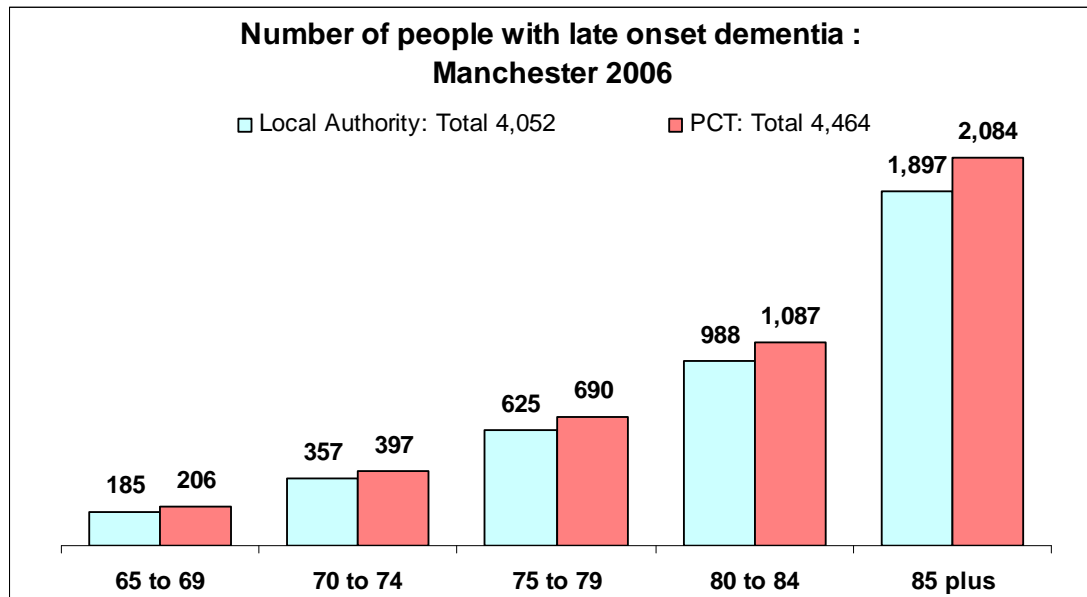
Modelled prevalence rates for all late onset dementia Manchester 2006

Age Group	Age specific prevalence rate	Population with late onset dementia	
		Local Authority	PCT
65 to 69	1.3%	185	206
70 to 74	2.9%	357	397
75 to 79	5.9%	625	690
80 to 84	12.2%	988	1,087
85 plus	27.1%	1,897	2,084
Total		4,052	4,464

Source:

Dementia UK Table 2.2 (Chapter 2 "The Expert Delphi Consensus on the prevalence of dementia in the UK") © Alzheimer's Society 2007

Sub National Population Projections Unit, ONS: Crown Copyright. Manchester JHU Population estimates for PCT relevant population based on ONS Sub National Population Projections



Source:
Dementia UK Table 2.2 (Chapter 2 "The Expert Delphi Consensus on the prevalence of dementia in the UK") © Alzheimer's Society 2007
Sub National Population Projections Unit, ONS: Crown Copyright. Manchester JHU Population estimates for PCT relevant population based on ONS Sub National Population Projections

As stated above these figures are likely to be under-estimates, for a number of reasons:

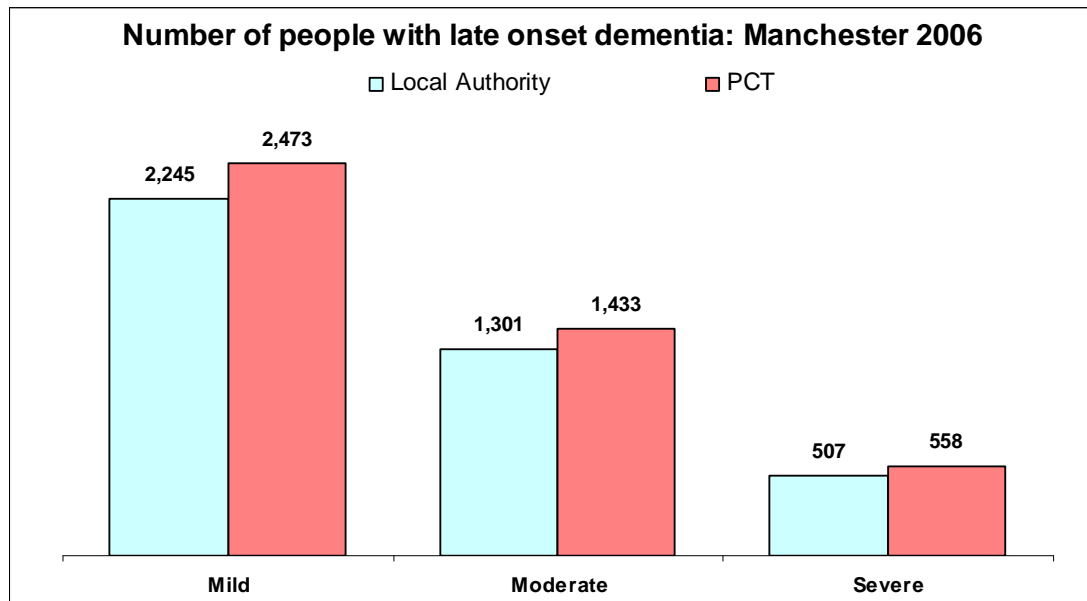
- Some national models estimate the prevalence of dementia as high as 10% of the 65+ population (in comparison to the 7.3% of the Consensus model). This would equate to around **5,200 people from the resident and 5,900 from the registered populations.**
- There is some evidence that dementia may be affected by environmental factors and by deprivation, although there is no solid consensus on this as yet. Manchester has featured in the "Top 5" deprived areas since 2000, when the first Index of Multiple Deprivation was published.

Late onset dementia - severity

The Dementia UK model:

Level of severity	As a percentage of all those with late onset dementia
Mild dementia	55.4%
Moderate dementia	32.1%
Severe dementia	12.5%

This can be represented in a chart as follows



However these are averages of severity across the age ranges. The Dementia UK report models severity at different rates for different age groups.

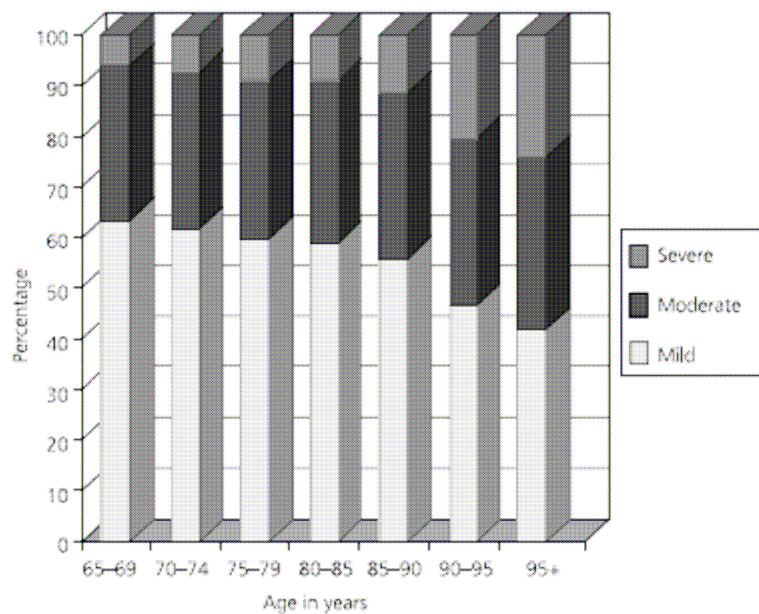


Figure 2.4 The consensus of the proportion (%) of cases of dementia in the population that are mild, moderate and severe

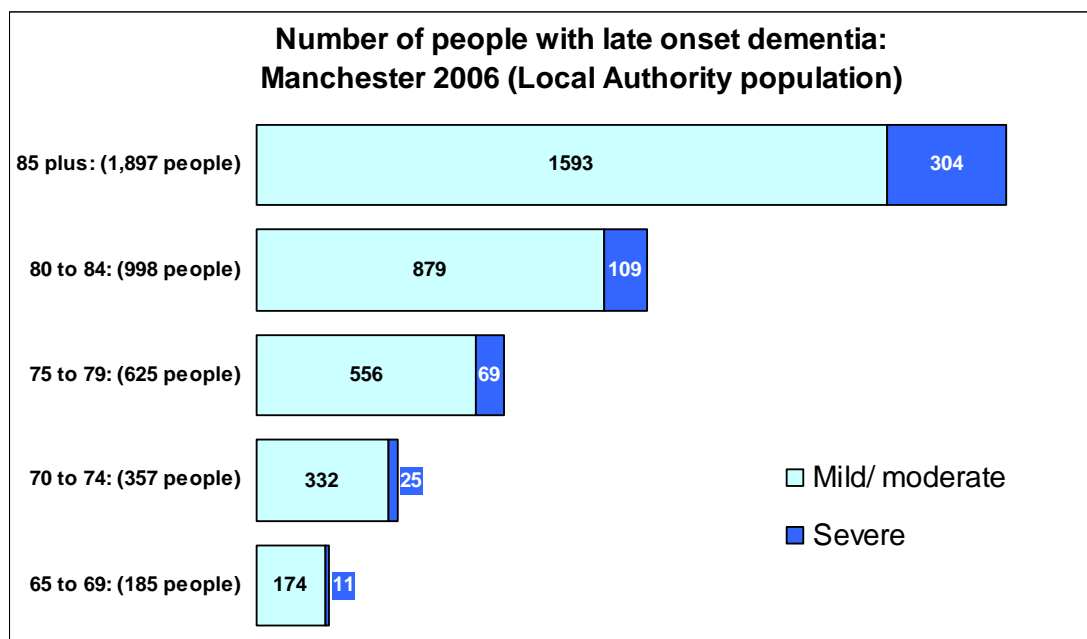
Source: Dementia UK © Alzheimer's Society 2007

The age related levels of severity work out as follows:

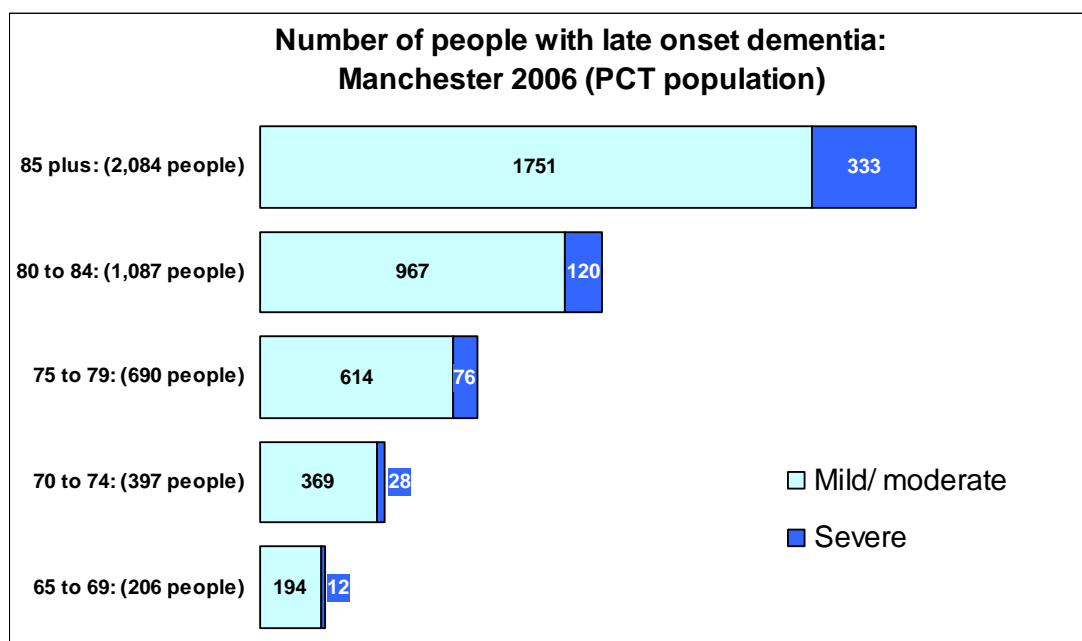
Age group	Percentage of those with dementia that are 'severe' cases
65 to 69	6%
70 to 74	7%
75 to 79	11%
80 to 84	11%
85 plus	16%

Source: Dementia UK © Alzheimer's Society 2007

The age specific proportions of people with dementia that is 'severe' are shown in the charts below.



Source: Dementia UK © Alzheimer's Society 2007. Sub National Population Projections Unit, ONS:



Source: Dementia UK © Alzheimer's Society 2007. Sub National Population Projections Unit, ONS:

Young Onset Dementia

The national model used to try to quantify young-onset dementia²² in Manchester (Table C below) illustrates the much rarer occurrence of these illnesses in the under 65s – approximately 82 people in the City (resident population). 90 for registered population).

Table C: Young Onset Dementia Prevalence in Manchester, 2006 (modelled)

Age Range	Female		Male		Total	
	Pop	People with dementia	Pop	People with dementia	Pop	People with dementia
18-29	62,501	0	65,364	0	127,865	0
30-34	16,419	2	19,800	2	36,219	4
35-39	15,254	1	17,083	1	32,337	2
40-44	13,879	3	14,845	1	28,724	4
45-49	12,398	4	12,248	4	24,646	8
50-54	9,876	5	10,629	7	20,505	12
55-59	9,783	10	10,229	18	20,012	28
60-64	7,941	9	7,425	15	15,366	24
Total	148,051	34	157,623	48	305,674	82

However, because the causes and the potential for prevention or recovery are much less clear than in late-onset disease, it is more difficult to be confident that the model fits Manchester's particular demographic and health profile.

²² From *Dementia UK*, Alzheimer's Society. February 2007. See Appendix 1 for the model.

We know, for example, that there is a strong link between alcohol abuse and some young-onset dementias, particularly Korsakoff's syndrome. Chronic alcohol abuse is thought to be responsible for 10% of all young onset dementia. Given that Manchester has one of the highest rates of alcohol consumption in England, particularly binge drinking,²³ it is likely that the Manchester prevalence is higher than the number taken directly from the model.

In more detail the formula is as follows:

Age in years	rate per 100,000
30 - 34	9.4
35 - 39	7.7
40 - 44	14.0
45 - 49	30.4
50 - 54	58.3
55 - 59	136.8
60 - 64	155.7

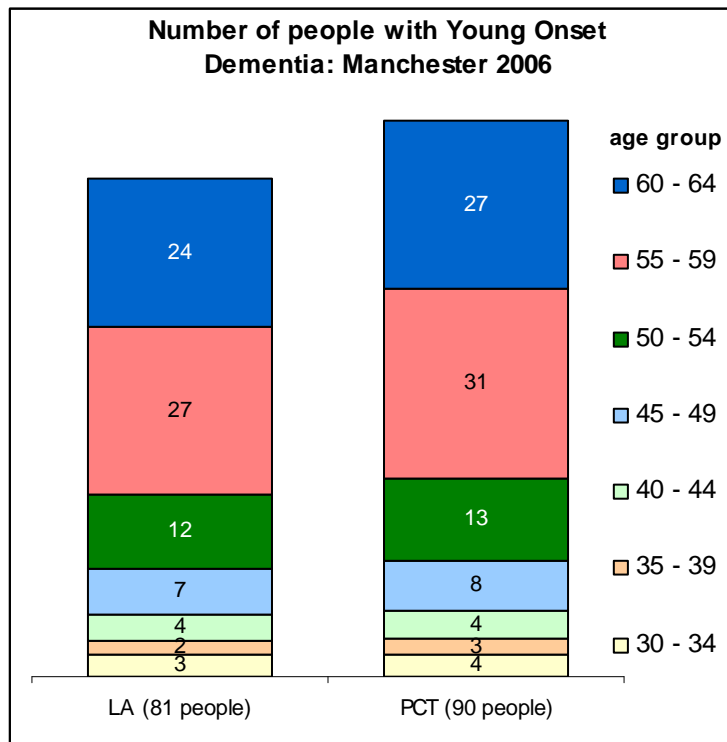
Source: Dementia UK © Alzheimer's Society 2007

Age in years	LA	PCT
30 - 34	3	4
35 - 39	2	3
40 - 44	4	4
45 - 49	7	8
50 - 54	12	13
55 - 59	27	31
60 - 64	24	27
Total	79	90

Source: Dementia UK © Alzheimer's Society 2007. Sub National Population Projections Unit, ONS:

²³ Working in partnership for good health in Manchester. Manchester Public Health Annual Report. 2006. Manchester Joint Health Unit. Jan 2007

Broken down by age bands this gives:



Source: Dementia UK © Alzheimer's Society 2007; 2001 Census Standard Table S001
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Predicting the future

The following table was produced by the JHU.

Projected estimate of the number of people in Manchester with dementia 2006-2016
Based on Expert Delphi Consensus on the prevalence of dementia (Dementia UK)

Year	Males			Females			Persons		
	Young onset (30-64 years)	Late onset (> 65 years)		Young onset (30-64 years)	Late onset (> 65 years)		Young onset (30-64 years)	Late onset (> 65 years)	
		All residents	Residents of care homes		All residents	Residents of care homes		All residents	Residents of care homes
2006	53	1,466	595	37	2,994	1,450	90	4,464	2,007
2007	54	1,495	603	38	2,972	1,442	91	4,484	2,017
2008	54	1,518	610	38	2,979	1,447	92	4,510	2,030
2009	55	1,547	619	39	2,956	1,438	94	4,515	2,034
2010	57	1,574	628	39	2,939	1,430	95	4,540	2,045
2011	57	1,603	637	40	2,907	1,415	96	4,528	2,041
2012	58	1,635	649	40	2,897	1,411	97	4,589	2,070
2013	58	1,684	668	40	2,887	1,406	97	4,611	2,081
2014	58	1,697	674	40	2,916	1,421	98	4,645	2,098

2015	59	1,732	687	41	2,908	1,418	100	4,689	2,119
2016	60	1,775	702	41	2,925	1,427	101	4,746	2,145

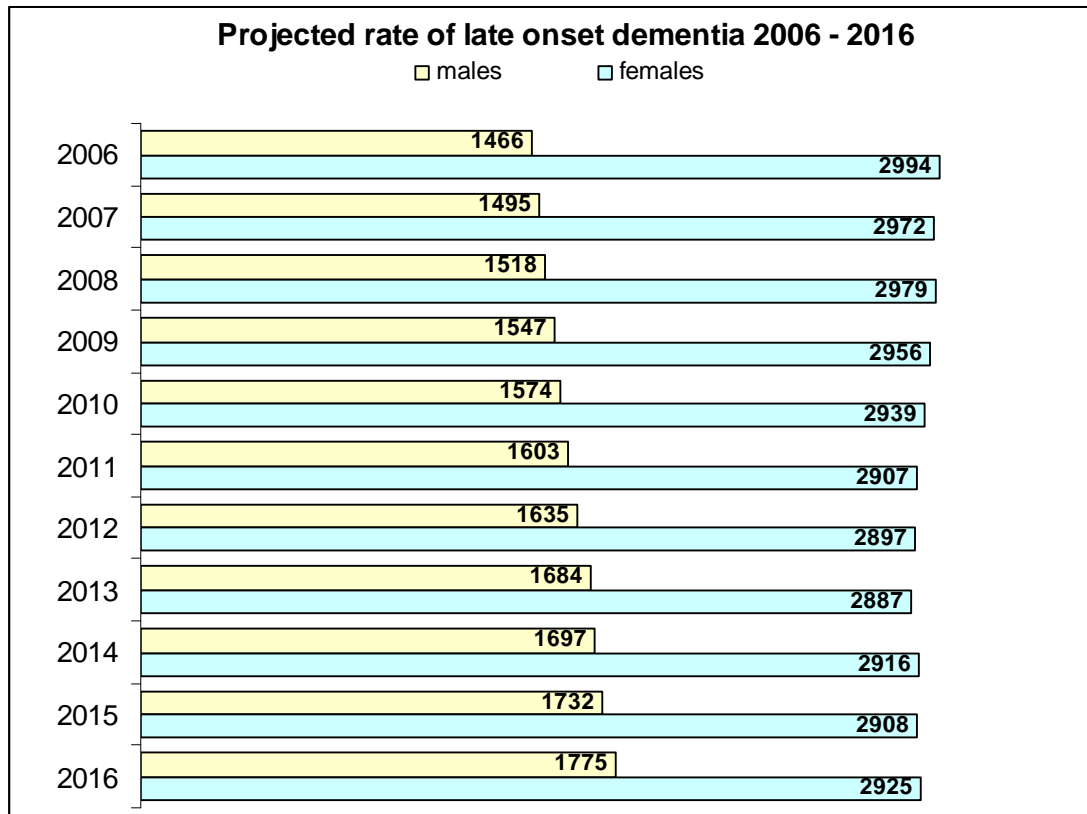
Source: Dementia UK © Alzheimer's Society 2007; 2001 Census Standard Table S001 © ONS.
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Patterns of use are based on current ones. Changing services may alter these, giving more opportunities for people to stay supported at home for longer.

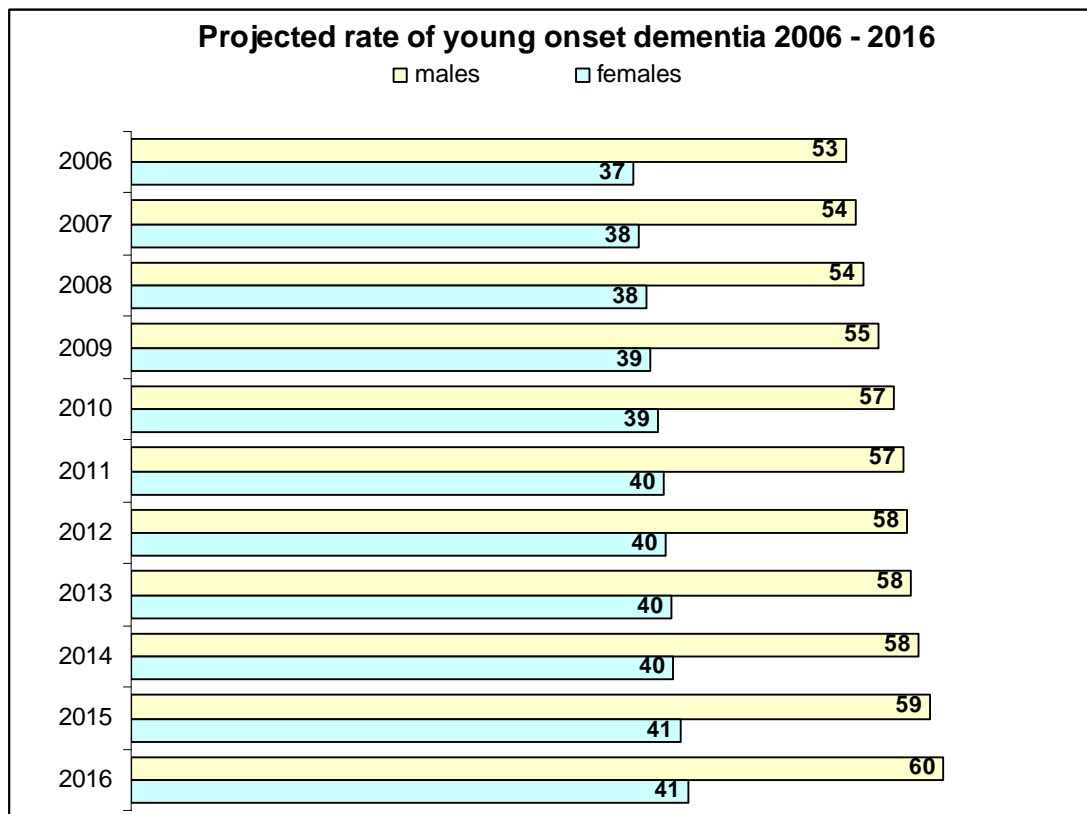
More crucial than these overall numbers is the proportions that are likely to experience **severe cognitive and/or physical impairment** and need intensive health and social care support. This will have significant consequences for dementia planning, including the demand for specialist nursing care "beds". Predicting future use based on actual current service use in Manchester, which was found to be similar to the Melzer model (mild = 17%; moderate = 49%; severe = 34%), it is possible to predict a growth in these numbers from approximately 1,350 of the resident population in 2006 up to 1,407 by 20215 – equivalent to an increase of 15 cases per year.

Table E: Prevalence rates and forecast numbers for mild, moderate & severe late-onset dementia in Manchester up to 2016

Year		Mild	Moderate	Severe	Total
2006	LA	675	1944	1350	3970
	PCT	736	2122	1472	4330
2008	LA	688	1982	1376	4046
	PCT	746	2151	1492	4389
2010	LA	687	1981	1374	4042
	PCT	746	2151	1492	4389
2015	LA	704	2028	1407	4139
	PCT	738	2126	1475	4339



Source: Dementia UK © Alzheimer's Society 2007; 2001 Census Standard Table S001 © ONS. Crown Copyright



Source: Dementia UK © Alzheimer's Society 2007; 2001 Census Standard Table