HALTON BOROUGH COUNCIL

Living Well With Dementia in Halton

Halton Dementia Strategy Needs Paper

2013-2018

CONTENTS

Introduction

This strategy needs paper highlights the national policy drivers and local needs analysis. It sets out current initiatives designed to improve the lives of people with dementia, their carers and families, enabling them to have a more fulfilled life and is the culmination of work led by the Dementia Partnership Board. The associated strategy paper and implementation plan shows how these drivers will be translated into action, and the outcomes. It is anticipated that the commissioning process will take five years in total to deliver and is a whole system transformation supported by collaboration of all agencies working to improve both the experience and outcomes of people with dementia and their families.

National Context

'Living Well with Dementia: A National Dementia Strategy' aims to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. Since its launch in 2009 the strategy has provided a catalyst for change at a local level with the vision of positive transformation of dementia services. Click here to see the national strategy.

The Prime Minsters Challenge on Dementia

Since the publication of the Joint Halton Dementia Strategy in 2009, the Coalition Government have set The Prime Minster's Challenge on Dementia (March 2012), to deliver major improvements in dementia care and research by 2015. The Prime Minister's Challenge on Dementia builds on the National Dementia Strategy to provide a framework which directs action. The goal is to make a real and positive difference to the lives of people affected by dementia. The ambition is to ensure that people with dementia and their carers receive high quality, compassionate care whether they are at home, in hospital or in a care home. The person with dementia, and their family and carer, are to be at the heart of everything health and social care providers do, with their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services for them. click here to see the Annual Report on Progress.

The Care Bill

The Care Bill was announced in the Queen's Speech in May 2013 and aims to modernise adult social care law, in order to clarify the issues of eligibility and service delivery. It is designed to create a new principle where the overall wellbeing of the individual is at the forefront of their care and support. To promote individual wellbeing, their needs, views, feelings and wishes should be considered in all aspects of their wellbeing from physical and mental health, through dignity and respect to control over their daily needs, access to employment, education, social and domestic needs and the suitability of their accommodation.

Whilst the Bill incorporates care and support across the board, when thinking about how dementia services are developed in the future, the Local Authority and health care partners will need to consider the following:

- access to services that help prevent their care needs from becoming more serious
- access to good information to help them make informed choices about their care and support
- have a range of good care providers to choose from
- the public know how to access independent financial advice
- the public know how to raise concerns over the safety or welling being of someone with care needs

Locally, it will require the integration of care and support with the local authority, health and housing services and other service providers to ensure the best outcomes are achieved for the individual. For example, care services will need to consider the strengths and interests of older people and to connect them to local clubs and social groups. This will strengthen communities themselves and helps to keep people safe and reduce, delay or prevent needs for acute care.

House Of Lords Committee on Public Service and Demographic Change report 'Ready For Ageing?'

The report published in March 2013 contained 10 principal conclusions and recommendations for action across Government. In particular the committee emphasised the need for Government to respond to the impact of our ageing population on public service provision. Dementia features heavily in the report, focusing on more ambitious targets for dementia diagnosis rates – to increase to two-thirds by 2015. Click here to see the report

NHS Operating Framework

The NHS Operating Framework 2012/2013 includes requirements for a renewed push on implementation of the national dementia strategy and increased support for carers. One of the key themes is putting patients at the centre of decision making and improving dignity and service to patients. The care of older people and dementia services are given priority within the framework and the move towards an outcomes focused approach provides incentives to improve services for older people. Local implementation of the proposed dementia Quality Outcome Framework indicators for 2014/14 places emphasis on the recognition and support of carers. Click here to see the NHS Operating Framework 2012/2013

National Outcome Frameworks

The Government's outcome frameworks provide accountability that focuses on how well services are improving outcomes for people. Locally this translates into monitoring how services are providing quality support that meets the needs of those with a dementia diagnosis, their family and carers.

The Prime Minister's Dementia Challenge has put the spotlight on improving diagnosis rates, research and the creation of dementia friendly communities. The NHS placeholder indicator 'Enhancing the quality of life for people with dementia' has been updated and extended. Accordingly, the 2013/14 NHS framework includes the two-part indicator, which measures diagnosis rate for people with dementia (there being evidence that receiving early diagnosis is important for people living with dementia, enabling them to cope better with their condition). A second complementary measure i.e. concerning the effectiveness of post-diagnosis care in sustaining independence and improving quality of life, is being developed. This indicator also appears in the Adult Social Care Outcomes Framework.

Data relating to the Public Health Outcomes Framework can be found at the Public Health Outcomes Framework data tool. As at September 2013 the baseline was still being established so there is no data available at this time. Click here to see the latest data for the outcome framework.

Public Health Outcomes Framework	**Adult Social Care Outcomes Framework**	**NHS Outcomes Framework**

4.16 Estimated diagnosis rate for people with dementia	Baseline Baseline data not yet published (baseline is not yet available as at Sept 2013)	1B. The proportion of people who use services who have control over their daily life	Performance 79.4% as at June 2013 (AQuA Benchmarking from Adult Social Care Survey)	1.5 Excess under 75 mortality rate in adults with serious mental illness	Baseline 850.7 (period: 2010/11)
		1D. Carer-reported quality of life	Performance 8.2 as at June 2013 (AQuA Benchmarking Carer's Survey)	2.1 Proportion of people feeling supported to manage their condition	Baseline Baseline Data not yet published
		2F Dementia - Effectiveness of post-diagnosis care in sustaining independence and improving quality of life (Placeholder)	Baseline Placeholder	2.4 Health-related quality of life for carers	Baseline Baseline data not yet published
		3C. The proportion of carers who report that they have been included or consulted in discussion about the person they care for	Performance 76.7% as at June 2013 (AQuA Benchmarking Carer's Survey)		
		3D. The proportion of people who use services and carers who find it easy to find information about services	Performance 75.8% as at June 2013 AQuA Benchmarking (Adult Social Care Survey/Carers Survey)		

Indicates Halton's performance is within the top 6 Authorities in the region

Indicates that Halton's performance is within 7-12 place within the region

Potential new indicators for the 2014/15 Quality and Outcomes Framework (QOF)

As part of a consultation that was undertaken in early 2013, there are 14 potential new QOF indicators being considered, 4 of which related to Dementia.

1. The percentage of patients with dementia with the contact details of a named carer on their record.
2. The practice has a register of patients who are carers of a person with dementia.
3. The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months.
4. The percentage of patients with a new diagnosis of dementia (after 1 October 2012) who have attended a memory assessment service up to 12 months before the date of diagnosis.

As part of the final menu of QOF indicators for 2014/15, GPs could be encouraged to record the percentage of patients with dementia who have attended a memory assessment service.

A new dementia indicator will encourage practices to record the name and contact details of the carers of each patient with dementia. This is to help improve communication between practices and other teams, such as out of hours care.

Practices could also be encouraged to measure the percentage of patients with a new diagnosis of dementia, with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded.

Comments received during the consultation were considered by the independent Primary Care QOF Indicator Advisory Committee in June 2013, along with the results of the piloting of these indicators across a representative sample of general practices. The Committee will then recommend which of these indicators should be considered for inclusion on the NICE menu for consideration for the 2014/15 QOF in September 2013. For the latest on QOF indicators please click here

Should the proposed QOF indicators be authorised , consideration will need to be given locally by practices on how they could impliment this guideline with the potential for poor access to this group of people. General Practices will need to follow best practise in making contact and arranging the tests, bearing in mind factors such as means of making contact and transport issues.

Local Context

The 'Living well with dementia in Halton ' strategy and implementation plan that accompanies this needs paper compliments other work programmes including the Halton Sustainable Communities Strategy, Mental Health Strategy, the Halton Health and Wellbeing Strategy, Carer's Strategy Action Plan, Falls Strategy and Loneliness Strategy, and should be read in conjunction with these pieces of work.

Halton Health and Wellbeing Board have prioritised Mental Health in their related strategy. The Halton Clinical Commissioning Group (CCG) also supports this priority.

The Halton Joint Strategic Needs Assessment identifies, as a priority, that the early detection and treatment of mental health issues should be improved as this will lead to a quicker recovery and reduce the negative impact on a person's quality of life.

The commissioning of initiatives that promote increased understanding of the needs for people with Long Term Conditions and mental health needs and develop integrated care pathways as a priority, as identified in the Halton Joint Strategic Needs Assessment.

Substantial impact on levels of ill health and costs to health and care budgets, as well as wider economy, can be achieved through integrated commissioning of services that meet the person centred outcomes as evidenced by NICE Dementia Quality Standards. Click here for the NICE Dementia Quality Standards

Performance

Diagnosis

Halton Clinical Commissioning Group Target

	Number of people diagnosed	Prevalence of dementia	% diagnosis rate	Current diagnosis rate (May 2013)
2013/14	**807**	**1300**	**62.1%**	**63.3% as at Nov 2013**
2014/15	**873**	**1323**	**66.0%**	

When comparing at estimated numbers, including those with early onset dementia, in practice-by-practice analysis, with 2012/13 QOF data released from the Health & Social Care Information Centre (The QOF register is all ages and may well include some with early onset dementia) the 63.3% CCG average diagnosis rate stands, with a range of 34.2% to 100%.

Later Life and Memory Service

LLAMS		Actual Activity							Agreed Plan 13-14		
	Service	Total Referrals Received	No. of Appropriate Referrals Received	First Contacts Seen	Total Contacts Seen	Total Contact DNA's	% Total DNA's	Total Discharges from Service	Full Year Total Contacts	Total Contacts	% Variance
Community	ECT				2				-	-	-
	LLAMS Assessment				68				1,242	104	-34.32%
	LLAMS CMHT				182				4,206	350	-48.07%
	LLAMS Liaison				49				820	68	-28.28%
	LLAMS Consultants				58				949	79	-26.68%
	LLAMS Memory				507				5,083	424	19.69%
	SALT				14				400	33	-58.00%
	LLAMS CH Liaison				110				-	-	-
	Total LLAMS Community	0	0	0	990	0	0.0%	0	5,483	457	116.67%

Social Care Support

Halton Borough Council (as at July 2013)

HBC Indicator	Description of Quarterly Monitoring Report Indicator	Actual 2011/12	Target 2012/13	Quarter 4
CCC 7 (Previously CCC 8)	Total number of clients with dementia receiving services during the year provided or commissioned by the Council as a percentage of the total number of clients receiving services during the year, by age	3.4%	5%	4.0%

	group.			

The Council target for providing social service support to people with dementia has not met, however performance is better than performance reported in the previous year (3.4%). It is clear that there are issues on how dementia is recorded within the councils customer management system, Carefirst. This is particularly challenging as people diagnosed with dementia may well have dual diagnosis and this may affect how they are categorised on Carefirst.

Number of People supported via the Dementia Care Advisor Service

	People that have been supported by the service
2012/13	359 people
Year to date 2013/14	189 people (up to end Sept 2013)

These are made up of new referrals to the service, therefore they will have been seen by a Dementia Adviser and some will be supported on an on going basis by the Dementia Support Worker (they have only been counted once). Of 2013/14 figures, 47 are people that just attend one of the activity groups.

Provision of informal information to people at events and over the phone are not included in the above figures.

Halton Dementia Profile

The term 'dementia' describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. There are many types of dementia. The most common are Alzheimer's disease and vascular dementia. Dementia is progressive and diagnosing dementia is often difficult, particularly in the early stages. The risk of developing dementia increases with age, and the condition usually occurs in people over the age of 65.

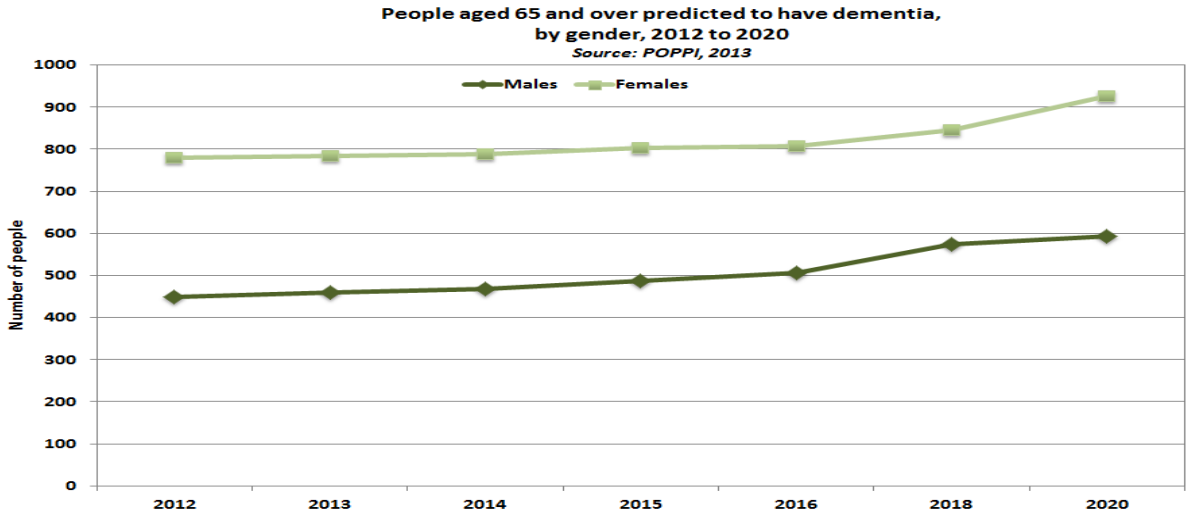
The population of Halton is aging. That is, a larger proportion of the total population will be found in the 60-plus age bands by 2031 compared to 2006. This section of the population will increase by 61% to 36,300 by 2031. This will then constitute 28% of the Halton population.

Dementia diagnosis and estimated prevalence

The number of people with dementia is set to rise by 62% by 2030, largely due to the projected increase in the older population. It is projected that there are 1,229 people aged 65+ living in Halton who have some form of dementia in 2012[1] and by 2020 this figure is estimated to be as high as 1518. In addition it is estimated that there are currently about 34 people aged between 30-64 who early onset dementia[i].

i Estimates from PANSI: Projecting Adult Needs & Service Information System: It is managed by the Institute of Public Care http://www.pansi.org.uk/

The graph below shows the estimated numbers of dementia patients by gender for Halton. There are predicted to be more females than male patients, and the greatest increases are in the 85+ age group. These projections, developed by POPPI[ii] and based on national research applied to Office of National Statistics population projections, estimate that the number of males aged 65+ diagnosed with dementia is set to rise from 449 in 2012 to 593 by 2020 and for females that rise is 780 to 925.



Diagnosing dementia in General Practice

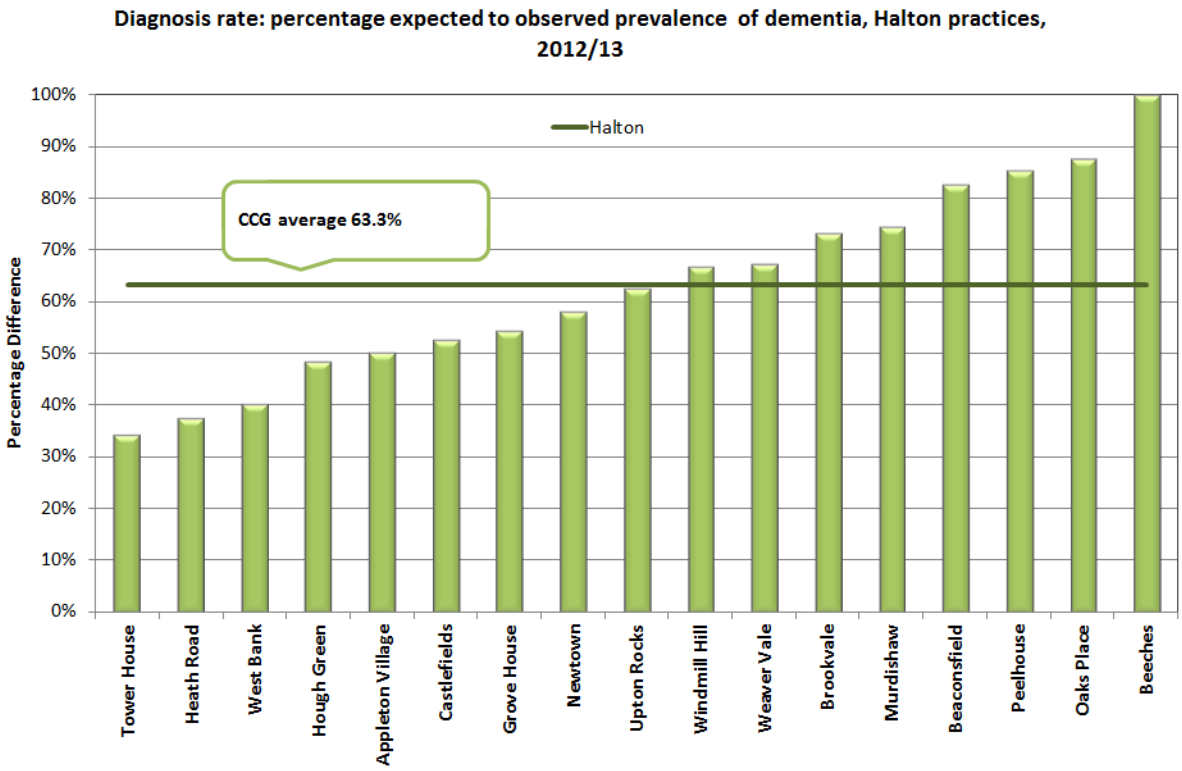
The GP contract includes the requirement for practices to establish a disease register for people with dementia. The diagnosis of dementia may be from correspondence with secondary care or via the GPs own diagnosis.

Quality Outcome Framework (QOF) data for 2012/13 indicates 747 patients registered at Halton GP practices as having dementia, an increase on the 2011/12 figure of 689 patients and 634 in 2010/11. Using the same age-specific prevalence rates utilised by POPPI (Projecting Older People's Population Information) and PANSI (for early onset dementia) and applying these to GP registered population gives an overall estimate for 2012/13 of 1,180 patients with dementia.

This method thus enables practice level estimates to be made which can then be compared to the dementia register numbers. This enables a diagnosis rate to be calculated (percentage of people diagnosed compared to expected/predicted numbers). Practice rates vary considerably from 34.2% to 100%. The CCG average rate was **63.3%.**

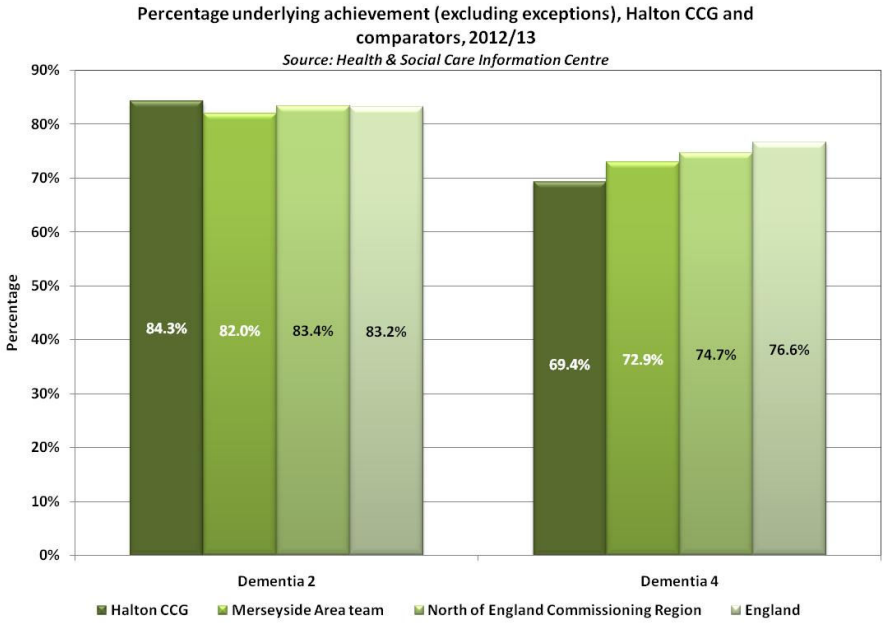
Whilst there has been an improvement there are still considerable levels of under diagnosis. Using this method suggests there are still 433 people with undiagnosed dementia in the CCG catchment.

ii POPPI = Projecting Older People Population Information System. It is managed by the Institute of Public Care http://www.poppi.org.uk/



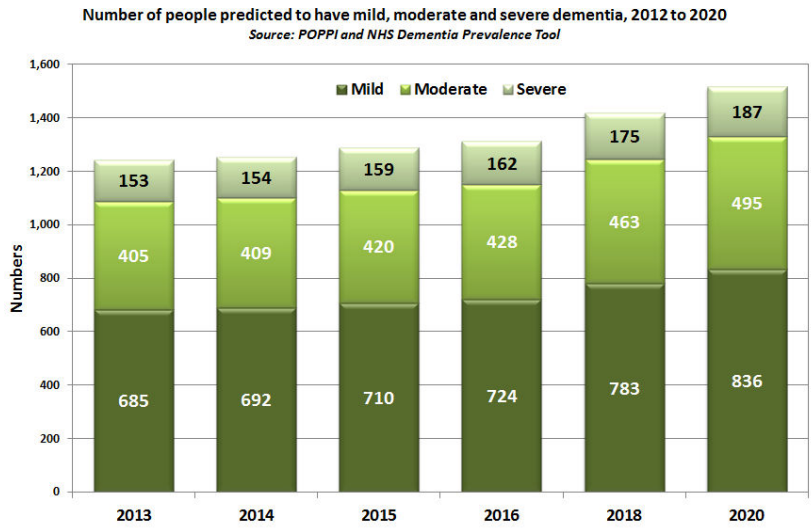
GP: Care Assessments

A further requirement of the GP contract is that patients on the dementia register should have had a care assessment within the previous 15 months. For 2012/13 Halton Clinical Commissioning Group (CCG) performance was 79.5%. This was above comparators (chart Dementia 2 indicator). For patients with a new diagnosis of dementia, practices are also required to record the percentage who have had FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded 6 months before or after entering on to the register (between the preceding 1 April to 31 March). For this indicator the CCG achievement was slightly lower than comparators (chart Dementia 4 indicator). There was wide variation across practices. For Dementia 2 indicator this ranged from 70%-100% with three out of the 17 practices achieving 100%. For Dementia 4 indicator the range was much wider 0%-100% (five practices achieved 100%). However, it should be noted that numbers per practice were very small for some practices. The total number of newly diagnosed patients for 2012/13 was 238 of which 180 were eligible for the tests and 125 received them. There were 58 exceptions, ranging from 0-8 per practice.



Different Levels of Severity

The Dementia UK 2007 report estimated that 55.4% of people with dementia have mild dementia, 32.1% moderate and 12.5% severe dementia. It also noted that these proportions change with increasing age with the percentage of those with severe dementia increasing and those with mild dementia decreasing. For example only 6.3% of dementia cases in the 65-69 age band are estimated to be severe rising to 23.3% in the 95+ age group. Using the NHS Dementia Prevalence Calculator tool, we can forecast numbers of dementia by severity in Halton.



Early onset of dementia

Dementia is rare before the age of 65, however, there will be a small number of people who develop the condition before this age. It is estimated that at age 30-34, 8.9 per 100,000 men and 9.5 per 100,000 women will develop dementia. This rate rises with each 5-year age band and equates to 33 people for Halton.

Although the numbers for early onset of dementia are low in Halton, these people are faced with a different set of challenges that include:

- Health care professionals generally don't look for the disease in younger patients and it can therefore be months or years before the right diagnosis is made and proper treatment can begin.
- Many people with early onset Alzheimer's and other dementia are still working when their symptoms emerge. Due to the nature of the condition, changes in their job performance or behaviour may not be understood or addressed. In addition the workplace can become a difficult environment.
- Those who leave their jobs before diagnosis may be denied certain Government assistance that would otherwise be provided to individuals with disabilities.
- Many individuals with early onset Alzheimer's and other dementia have low incomes and are in need of assistance, but have a difficult time getting it.
- Existing healthcare, home care or community service provision may not be appropriate for early onset individuals

Family members and other carers often lack the information and support they need to provide care to the person they support.

Dementia beds

Halton has a 244 registered dementia beds in residential and nursing homes, 82 of these are dual registered. There are also 249 nursing beds available of which 196 are registered as EMI Nursing. It is not clear how many of the residents in residential care have dementia, national research from the Alzheimer's Society suggests that underreporting could lead to 80 % of people in residential care actually have some form of dementia, if we compare this to figures based on National Audit Office research, they estimate that of the 1,180 residents thought to have dementia in Halton 788 will live in the community and 392 in a care home. It is estimated that by 2030 1,367 people diagnosed with dementia will be living in the community and 683 will be requiring care home places.

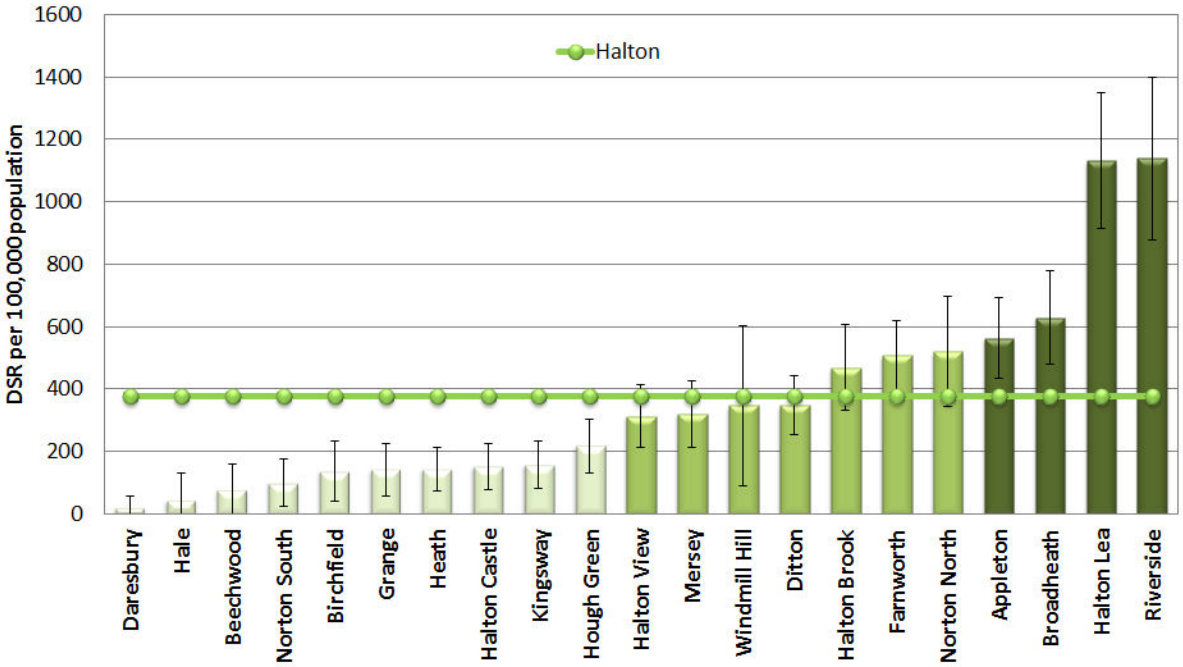
Work is required to fully assess the current registration levels of care homes in Halton.

Hospital admissions due to dementia

Few people are admitted to hospital primarily due to dementia. In total 747 people across Halton who were admitted to Hospital during 2012/13 had some form of dementia (only 76 had dementia as the primary reason for the admission). This is an increase on the 2011/12 figure of 563, with the figure for 2010/11 being 705. This figure for 2012/13 included 39 admissions for people under the age of 65. Some of these may be one individual who is admitted multiple times throughout the year.

Rate of hospital admissions (DSR: Directly Age Standardised Rate, per 100,000 population, all ages) for Dementia (primary and secondary diagnosis codes 1-5), 2012/13

Source: SUS data, 2013



In Halton during 2012/13, 76 people were admitted to hospital with a primary diagnosis of dementia. However many older people with dementia will have more than one health problem. As such some people admitted for another health reason will also have dementia. This is likely to have implications for the support they need both whilst in hospital and how to manage / level of care needed once they leave hospital.

Social Care

Key findings from the National Audit Office's 2007 *Improving Services and Support for people* with dementia indicate that almost two thirds of patients live in the community and one third are in care homes. If we apply this to Halton data it would suggest that there are 793 people living in the community and 427 in a care home. However, if we consider data from carefirst there are only 308 people identified with dementia. 113 are supported in the community and 195 are in residential care.

The above data collection issues may well be the main reason for the reduction in the number of clients with dementia who have received a review. Although year on year there has been a slight increase the trend has been downwards for a period of six years.

It is clear that there are significant differences in the estimated to the actual figures. At first reading it might be pertinent to suggest that there is some significant under delivery within the system, however, this may attribute for a small amount, but the bigger issue is the quality of the data collection and inputting at source.

clients receiving nursing care has fallen from 32% in 2005/06 to nearly 18% in 2011/12; this represents a decrease in both percentage totals and number of people with dementia.

Of the clients receiving community based care nearly half received home care during 2011/12, just under a quarter received day care, meals and professional support and just under half received some other form of service for example, wardens, equipment etc.

A1: Number of clients with whom a review was completed during the period, by age group

	2005/06				2006/07				2007/08				2008/09				2009/10				2010/11				2011/12			
	18-64	65-74	75+	Total	18-64	65-74	75+	Total	18-64	65-74	75+	Total	18-64	65-74	75+	Total	18-64	65-74	75+	Total	18-64	65-74	75+	Total	18-64	65-74	75+	Total
Dementia	5	30	140	180	10	35	140	185	15	25	110	145	15	15	100	130	15	10	95	115	10	15	95	120	10	20	95	125
Mental Health Total	260	80	275	615	270	75	255	600	380	80	215	680	310	60	180	550	330	55	150	535	325	65	155	545	325	60	150	535

It's important to note that the number of clients receiving various services does not add up to the total number in receipt of services as many clients will receive more than one service.

click here to see the full Halton Dementia Profile produced by Public Health

Cost of Dementia

Dementia UK found that the total costs of dementia in 2007 amounted to £17.03 billion per annum. Since 2007 the total cost of dementia has continued to rise: updated figures for 2012, published with the Society's Dementia 2012 report, put the cost at £23 billion with 800,000 people living with the condition, with an average cost of £29,746.

The Dementia UK report [2]estimated that the total annual cost per person with dementia in different settings in 2007 was as follows:

People in the community with mild dementia - £14,540

People in the community with moderate dementia - £20,355

People in the community with severe dementia - £28,527

People in care homes - £31,263.

Over a third of the total cost (36%) was due to informal care inputs by family members and other unpaid carers. Not included in this amount is the estimated £690 million in lost income for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer. Accommodation accounted for 41% of the total cost.

The greatest proportion of direct costs of dementia care is associated with institutional support in care homes. This is often provided at a crisis point, is always costly and often precipitated by a lack of effective support.

Data collection within the local authority is such that it is difficult to assess the exact number of people with dementia in receipt of a personal budget. However, a national study identified that uptake of personal budgets among people with dementia still lags behind most other client groups. Three in five people with dementia assessed as eligible for a care package were not even offered a personal budget, while 15% declined an offer of one, found a study by Alzheimer's Society [3]. The perceived risk of financial abuse; issues of capacity; lack of information and support for families and carers, and the fact that many people with

dementia only access social care at crisis point – when setting up a personal budget is more complicated – have all been put forward as causes.

A report by the Mental Health Foundation[4] has shown that individualised, tailored support and care that a personal budget can facilitate can have enormous benefits to a person with dementia.

Considerations when assessing a person with a dementia diagnosis for a personal budget should include:

- Training for social work staff specifically on personal budgets and how they can work for people with dementia
- Support social workers, individuals and carers to really understand what support is available in the marketplace so that they can ensure outcomes really match individuals' wishes.

The costs of delivering personal budgets to people with dementia are higher than some other care groups. With uncertainty regarding the social care budget in the context of cuts across the whole of the public sector, personal budgets for people with dementia will need to be introduced with great care and within the realistic context that resources are limited. The additional costs of brokerage and managing the money need to be considered by the local authority.

Prevention

The strength of evidence around dementia prevention is currently not very strong. However, the evidence that is available suggests that the most promising approach to reducing the prevalence of all forms of dementia is a more general promotion of healthy lifestyles, particularly for those in mid-life. It has been estimated that by promoting and adopting healthy lifestyles in middle age, an individual's risk of developing dementia could be reduced by approximately 20%[5]. Other research suggests that decreasing the prevalence of risk factors including midlife hypertension, poor educational attainment and depression, could have a positive effect on the prevalence of Alzheimer's. American researchers[6] analysed the strength of the association between these factors and Alzheimer's and showed that cutting down these risk factors by 25 per cent could reduce Alzheimer's cases by 3 million worldwide.

While it is not possible to prevent all cases of dementia, there are some measures that can help prevent vascular dementia, where problems with blood circulation result in parts of the brain not receiving enough blood and oxygen. According to a World Health Organisation report in 2012 [7], research identifying modifiable risk factors of dementia is in its infancy, but prevention should focus on countering risk factors including diabetes, midlife hypertension, midlife obesity, smoking, and physical inactivity.

Evidence also highlights the value of early intervention and diagnosis, as up to two thirds of people and their families are living with dementia unaware of its existence[8]. Early intervention, both pharmacological and non-pharmacological, can help to slow the progress of dementia and its symptoms. It can also help to better prepare individuals and their families for the future of living with the condition.

Any interventions that could reduce the burden of the condition by preventing or delaying the onset of dementia could not only provide health and well-being benefits to the person with dementia, but to society in terms of reduced carer responsibility and improved productivity, and also the public purse in terms of reduced health and social care costs. This is especially pertinent with regards to an increasing population of older people projected for Halton.

There are a number of local actions being implemented as part of Halton's Sustainable Community, Health and Wellbeing, Mental Health and Loneliness Strategies that are key to tackling both the

Developing dementia friendly communities

Evidence from the Alzheimer's Society report '**Dementia-friendly Communities:** A priority for everyone' [9]suggests that many people with dementia do not feel supported and a part of their local area. Findings from a recent Alzheimer's Society and YouGov Poll suggest that:

• Less than half of the respondents to the Dementia Friendly Communities survey think their area is geared up to help them live well with dementia (42%).
• Less than half feel a part of the community (47%). Results become considerably lower the more advanced the person's dementia is.
• People from seldom heard communities expressed complex issues around feeling part of their community. Stigma was particularly highlighted by people with dementia and carers.
• More than half of UK adults surveyed in the YouGov poll feel that the inclusion of people with dementia in the community is fairly bad or very bad (59%).
• Nearly three quarters (73%) of UK adults surveyed in the YouGov poll do not think that society is geared up to deal with dementia.

During the life course of the strategy that accompanies this needs paper, Halton will be working towards becoming a dementia friendly community. That is, a community that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives, contributing to better outcomes for people with a dementia diagnosis, their families and carers.

Raising Awareness

The Alzheimer's Society has developed a range of literature to support a local public information programme drawing on, and aligned with the national campaign and will includes awareness of the risks of developing dementia at a younger age.

The Bridgewater Community Health Care Trust's Live Life Well website is being promoted as a central source of health and wellbeing self help resources, information and links services. There are resources and information relating to dementia contained in the Mental Health Directory on the site.

Consultation tells us that self-help resources, information and links to services will enable individuals, their family and carers to access information at the appropriate time and understand what services are available to them. This may go some way to addressing the sometimes common misconception that there are no, or limited, services to support people with dementia once a diagnosis has been made.

Like Minds Campaign

Halton Borough Council and Halton Clinical Commissioning Group have lead on the development of a local intergenerational anti stigma campaign, 'Like Minds', which was launched on World Mental Health Day 2013. The campaign aims to tackle perceptions of mental health generally, and has a call to action of encouraging people who may be suffering with the early signs of mental health problems to talk (to anyone, not just their GP) to share their concerns, thoughts and feelings and seek help.

The campaign will offer information about where support can be sought and direct people to the information, services and self help resources available from the livelifewell website, managed by NHS Bridgewater Community Health Care.

This campaign targets carers (including carers of people with a dementia diagnosis) and people hwo may be vulnerable to a dementia related illness, who may be at a greater risk of anxiety and depression related mental illness.

Dementia Training

Halton Broough Council has been successful in a recent funding application to deliver bespoke training in dementia via Skills for Care. This project will focus on:

1. Raising awareness of dementia across the whole community, by bringing local people and professionals together in two planned events;

2. Using the Family Carers Matters and People with Dementia Matter courses, life story training will be provided to individuals with dementia and their carers.

3. Sessions will be held with Housing Providers that will include managers and front line staff, one at the beginning (September 2013) and one in March 2014 with a view to establishing a commitment from providers to develop a coherent housing response to the local dementia strategy;

4. Working with local tenants, using the Volunteers Matter course, training will be provided to support them in recognising the needs of people with dementia and enabling them to provide additional support;

5. Develop the skills and confidence of GPs, managers and staff in the Well Being Practices (CCG);

6. Aligning this with our work on re-commissioning domiciliary care, we are offering training, using the Your Story Matters approach, on the value and impact of life story work to underpin a person centred approach to care.

The training will be developed from August 2013 until March 2014.

This training may contribute to the reduction in use of antipsychotic medication (through life story work) and equip professionals and the public with the skills to provide support to people with a dementia

Early Diagnosis and Support

NHS Health Check

The NHS Health Check programme aims to help prevent heart disease, stroke, diabetes, kidney disease and certain types of dementia. Everyone between the ages of 40 and 74, who has not already been diagnosed with one of these conditions or have certain risk factors, will be invited (once every five years) to have a check to assess their risk of heart disease, stroke, kidney disease and diabetes and will be given support and advice to help them reduce or manage that risk. From April 2013, as part of the NHS Health Check programme, people aged 65-74 are given information about dementia at the time of risk assessment to raise their awareness of dementia and the availability of memory services.

The intention is to raise awareness of memory assessment clinics for those attending an NHS Health Check.

5 Boroughs Partnership Later Life and Memory Service

In June 2013 the redesigned Later Life and Memory Service (LLAMS) pathway was implemented in Halton. Initially a pilot was agreed and this was run in the Wigan Borough until mid-September 2012. The pilot involved re-configuring existing teams and services to deliver the new model for community focussed dementia care.

Preliminary analysis of the Wigan pilot's findings demonstrated that the changes introduced delivered a positive impact upon service efficiencies and the timeliness of response to referrals. That contributed to a positive experience of the new service for Service Users and Carers. Similarly, there is evidence to show that collaborative working between staff and the integration of teams improved the speed with which diagnoses were arrived at, the availability of support for the management of memory problems and an increase in the levels of support provided within community settings. Further detailed analysis will be needed however before firm conclusions can be drawn about the long-term impact of the new model of care and care pathway upon the likely demand for in-patient care. During the pilot period however, there was a reduction in the need for in-patient care, although those requiring it exhibited more complex needs. Similarly, the pilot appears to support the new service model's assertion that increasing the availability of community-based support and the therapeutic approaches of in-patient teams will result in shorter lengths of stay for service users within in-patient care.

The following specific key findings were observed:

The service received between 100-120 referrals each month (in-line with same period in 2011)

96% of referrals were non urgent

80% of referrals were seen within the 10 working day target (typically, where the 10 day target was not met this was because of a Service User request for a later appointment)

35% of Service Users were referred onwards to the memory function

30% of Service Users had more complex needs and were referred onwards to the Community Mental Health Team function

35% of the Service Users referred benefitted from the service's short term interventions and were then discharged back to primary care

Of the 60% of face-to-face contacts for which the time of contact was recorded, only 4.5% took place during extended opening hours

In-patient units within the pilot area experienced:

Occupancy levels well below capacity (67.5% on average during the pilot's first 3 months)

a reduction in length of stay per episode (this fell by 8 days to 44.6 over the pilot's first 3 months)

Service Users' self-reported experiences of the service were positive

There were increased levels of collaborative working between Trust teams, and Trust teams & external agencies (local authority and acute Trust teams for example). It appears that increased collaborative working directly contributed to the perceptions of service quality (on the part of Service Users and Carers), and staff satisfaction (by Trust staff)

A Primary Care pathway has been developed and is now being used. The pathway can be found in appendix 1

The enhanced service has been designed by the NHS Commissioning Board to support practices in contributing to system wide improvements by supporting timely diagnosis, supporting individuals and their carers an integrated working with health and social care partners.

The assessment for dementia offered to consenting at-risk patients shall be undertaken following initial questioning using the 6CIT (Cognitive Impairment Test) to establish whether there are any concerns about the attending patient's memory.

For the purposes of this enhanced service, 'at-risk' patients are:

- Patients aged 60 or over with cardiovascular disease, stroke, peripheral vascular disease or diabetes
- Patients aged 40 or over with Down's syndrome
- Other patients aged 50 or over with learning disabilities
- Patients with long-term neurological conditions which have a known neurodegenerative element, for example Parkinson's disease.

This enhanced service will be reviewed for 2014/15 in light of possible changes to the Quality and Outcomes Framework (QOF) for 2014/15.

The aims of this enhanced service in 2013/14 are to encourage GP practices to:

1. Identify patients at clinical risk of dementia;
2. Offer an assessment to detect for possible signs of dementia in those at risk;
3. Offer a referral for diagnosis where dementia is suspected; and,
4. Support the health and wellbeing of carers for patients diagnosed with dementia.

In Halton, 16 out of 17 GP practices have signed up to the scheme.

Community Dementia Care Advisors

A key development since the launch of the dementia strategy is the successful commissioning and implementation of the local Dementia Care Advisors and Dementia Cafés.

The service is delivered in partnership by the Alzheimer's Society and Age UK Mid Mersey, drawing on the learning from the Department of Health National Dementia Advisor pilots to deliver positive outcomes for people living with dementia and their carers. Following consultation days people with dementia and their carers highlighted what they wanted from the service; which included the following

- Provide timely information and advice for the carer and cared for
- Provide individualised and timely practical and emotional support for the carer and cared for
- Improve communication between professionals/services in order to reduce unnecessary service duplication and enhance partnership working

The service has been developed to ensure that individuals are kept informed of their choices throughout the dementia journey so that they do not fall through the net and out of the system which will then prevent them going into crisis.

The service offers a pre diagnosis advice service and post diagnosis support including information, awareness and advice, signposting to services and supports, continued consultation, planning and involvement, as well as supporting the development of peer support, group sessions, self-help/ expert patient approaches, the development of user and carer led services and educational programmes.

In addition the service provides a highly responsive information and signposting support service to people with dementia as the first priority, and to those who support and care for them. The role of Dementia Care Advisor is the key person who is responsible for coordinating all the services available to the service user ensuring that agencies and professionals communicate with each other over the delivery of their services.

The service currently has a capacity of 1,200 face-to-face contacts with service users in Halton per annum. Of these some only require initial support and signposting but others need more comprehensive on-going support and case management and the Dementia Advisor ensures that the service user is navigated through the system to ensure that the whole service available is coordinated with all relevant agencies.

The Dementia Care Advisor service works in partnership with key stakeholders and partner services including primary health care services, primary mental health care, adult mental health, older persons social care services and third sector services. The Dementia Care Advisors although based within Alzheimer's Society and Age UK offices also have a presence within the Later Life and Memory Service locations (currently the Norton Day Unit in Halton).

In June 2013 the Halton Dementia Support service and Dementia Adviser service evaluation questionnaire was sent out to a random selection of 100 service users who have within the current contract engaged with services.

The questionnaire was designed to gain an understanding of how both carers and people living with dementia feel about the service that the society provides to them in relation to both the Dementia Support Service and the Dementia Adviser Service. There was a 52% response rate.

Overall it seems that from questionnaire responses, people who are accessing services from Alzheimer's Society in Halton are happy with the service they receive. It's clear that people feel that they are listened to

and treated with respect and dignity. In addition to this people feel that they have received clear and easy to understand information which is useful.

It seems that service users appreciate the different roles that the Dementia Adviser and the Dementia Support Worker offer as some people enjoy the weekly emotional support which the activity groups offer whilst others want the more practical or written information which the Dementia Adviser is able to provide.

It is also clear that the information which is provided upon diagnosis by the Dementia Adviser is more comprehensive than information given by the health service and this information is a lot easier to understand.

"I found that the Dementia Adviser offered more information than any other service we have come into contact with"

"I have enjoyed meeting new people every Friday"

"The Dementia Adviser who visited me was easy to speak to and didn't use jargon"

"The Dementia Adviser involved my mum in all aspects of our meeting. Myself as a carer learned more in the 1.5 hours spent with the Dementia Adviser than I have in the countless meetings with other

"More equipment at activity groups to stimulate those with dementia"

"Social outings for carers and people with dementia"

"I would like to attend a course to learn more about my condition"

"I would like half an hour sing-along incorporated into the activity groups"

Needs analysis and business cases are being undertaken during quarter 2 of 2013/14 for further development of the Dementia Care Advisor service, along with Reader Groups and the requirements for a late night dementia respite provision. This will identify where resources could be targeted to ensure the needs of people with a dementia diagnosis and their carers are more fully met.

Advancing Quality Alliance (AQuA)

Halton has committed to be an active partner in the AQuA Living Well with Dementia Programme for 2013/2014 and are working with leaders in the field to develop needs analysis and business cases for dementia provision locally.

This work will contribute to addressing fear and perceptions associated with receiving a diagnosis of dementia by aiding the development of appropriate, seamless services to meet the real needs of people with a dementia diagnosis.

Research has been undertaken to identify exactly what the key points of intervention for carers are and what types of information, advice and support they require at these junctures [10].

The evidence has highlighted a number of critical points when carers' needs for information, advice and help are particularly acute – and these are also points at which they are likely to encounter professionals and service providers. This means that all professionals and service providers will need to check that carers have the information and advice appropriate for the challenges they are currently experiencing and that they know where to go for further information and advice when future difficulties arise. Failure to recognise carers' needs at these points risks the breakdown of care-giving and the carer's health and other costs for carers and wider society. What is clear from the report is that integration of health and social care information, services and follow up is key to providing a holistic service for the carer. Information provided at the right time, with detail of who to contact for more information is key.

Work undertaken by the Council's Customer Intelligence Unit (Carer's Discussion Groups) highlights the needs of Halton carers generally, in relation to provision of information and support. Often carers of a person with a dementia diagnosis report of receiving too much information in one go, much of which may not be relevant to them or their loved one at the time, or not receiving the much information at all. The role of the Halton Dementia Care Advisor will be key to supporting access to information and assistance in interpreting that information.

Findings from the Carer's discussion groups include:

- Make sure that information about 'Formal' carers groups provided to carers directly and via networks is timely and consistent.
- How can we use current networks and carers to communicate and engage with hidden carers, young carers or those carers who do want / cannot attend meetings?
- Perception of a lack of trustworthy knowledge about specialist conditions / or who to ask for the information
- Listening to carer opinion when discussing health treatment – What about an 'official carer' card – so that professionals can share information with the carer.
- Too much information given / no support / expected to remember everything that was discussed.
- Assessment: lots of agencies and professionals visiting - becomes stressful not knowing who you are talking to person they care for.

C ol whereby carers can ask questions about and provide feedback on their care to health and social care professionals. It is anticipated that the results of the first round of questions and the usefulness of the tool will be available towards the end of 2013.

Carers will be encouraged to use the forum, accessing timely professional advice and the opportunity to provide feedback, on which services can further develop to meet the needs of those who utilise them.

Carers Assessments

Work is currently being undertaken to streamline the process through which carers are assessed and access direct payments to fund a break away from caring. Once in place the revised arrangements will have a significant positive effect on those individuals who care for people with dementia.

Current Council data shows that 4.9% of carers on the Carefirst system receiving a Direct Payment are caring for a person with a dementia diagnosis.

Dementia Support Service (part of the Positive Behaviour Support Service)

'Active Support' is one approach to increasing engagement, and increasing independence that has received much attention with learning disability populations. This is a system that relies on structured daily activity planning, and graduated levels of support and assistance based on the individual's needs to increase activity. A recent research project in Halton Borough Council's Oak Meadow day service conducted by members of the Positive Behaviour Support Service [11] found the Active Support approach to be equally as effective with people with dementia. They found significant increases in social interaction, and in domestic, personal care and leisure activities of the service users. Although the greatest statistical gains were found with the most able (most recent onset) service user, more socially significant effects were evident for the person in the latter stages of the illness.

The 'Living Well with Dementia' national strategy objectives identify goals for improving dementia services such as home care, carer support, intermediate care, residential care and end of life care. The work of a Behaviour Analyst has the potential to enhance support in the community and in care settings.

Care at hospital

During 2013 Warrington Hospital was successful in their bid for Dementia Care Scheme funding. The total value of the funding is £1,053,322, which will be used to transform the care environment for patients with dementia in the hospital. Plans for the funding include a redesign of an existing ward at Warrington Hospital and a new garden area to promote relaxation, stimulation and a calmer environment for patients with dementia.

Funding comes from a £50 million fund from the Department of Health for projects that demonstrated how practical changes to the environment within which people with dementia are treated in will make a tangible improvement to their condition.

The projects will form part of the first national pilot to showcase the best examples of dementia friendly environments across England, to build evidence around the type of physical changes that have the most benefit for dementia patients.

Role of the Fire and Police Services

Older people are significantly more at risk from fire and account for higher representation in the numbers of fire deaths than any other group.

- Within the over 80 age group risk increases significantly, particularly for those living alone.
- Males living alone are at greater risk than same age females and therefore at ages below 80.
- The risk of fire related incidents increases with bereavement
- Fire risk will increase as other vulnerabilities and risks affecting independence start to emerge, including those associated with a dementia diagnosis.

Extensive work has been undertaken locally by Cheshire Fire Service in developing their partnership working with Age UK . Briefing and referral information has will be continue to be widely distributed to professionals, landlords and the public detailing fire related advice available for older people, and those with a dementia diagnosis. The Fire Service also provided fire related advice and support to all Care Quality Commission registered providers in the past 12 months.

Cheshire Fire Service currently joint fund two dementia advisors, one in Cheshire East and one in Cheshire West and Chester. These are co-funded with CCG's and Age UK Cheshire but could potentially replicated with a number partners, including Halton.

Working with the Fire Service will form an important part of developing dementia friendly communities

Cheshire Fire Service are exploring 'dementia friends' training for their advocate teams to better meet the needs of people with a dementia service accessing Fire Services.

Cheshire Fire Service are exploring a transition from hospital to home pilot in Macclesfield, and the support that can be offered by the Fire Service to vulnerable older people, including those with a dementia diagnosis. This may provide a learning opportunity for Halton to review how the Fire Service can further support vulnerable people in Halton.

Delivering the Dementia Strategy

Development of a performance dashboard

There are few national and local indicators that expressly measure the impact on people with a dementia diagnosis or carers of people with a dementia diagnosis. Whilst inferences can be made, links are not explicit. In addition, much of the data in the national indicator set is captured annually, and therefore will not make suitable indicators for a 'real time' dashboard.

A performance dashboard is currently being developed by the Halton Dementia Partnership Board to assess progress and improve outcomes for people with a dementia diagnosis and their carers against the 8 Halton Dementia Pledges. Two sources of information will be used to inform progress against improved outcomes. These are:

- Metrics, for example, the diagnosis level in relation to prevalence;
- Qualiative information on the experience of people with dementia, their family and carers

Gap Anaylysis

Providers have told us[12] that they are increasingly seeing individuals presenting with very complex needs. It has been suggested that there is increasing demand for a number of placements/beds for people that do not require hospital or a specialist placement but need more than the usual residential/nursing care and at times one-to-one care. As the number of older people with increasing complex needs is set to increase, there is some urgency to identifying current and future local need and developing the local market to meet increasingly complex needs. Further exploration between Commissioners and Providers is required.

Work has already been undertaken as part of the Halton's Joint Strategic Needs Assessment that identified the following key issues and gaps in relation to Dementia;

Improving public and professional awareness and understanding of dementia

Gaps include the quantity, quality and frequency of information that is available. There are also possible gaps within information that would support early diagnosis and access to improved community services. In

relation to community services there is a gap in specialist knowledge that often leads to people with dementia being unable to access some generic community services and facilities.

Good-quality early diagnosis and intervention for all

There are no designated teams specifically designed to address early diagnosis and intervention. However, this is being addressed through the development of the Assessment, Care and Treatment Service.

Good-quality information for those with diagnosed dementia and their carers

Information is available; however it needs to be consistent, timely and widely available for people with dementia and their Carers.

Development of structured peer support and learning networks

Capacity for the Dementia Peer Support Network will need to be monitored to ensure that there are appropriate levels of service provision.

Implementing the Carers' Strategy

The specific needs of carers of people diagnosed with dementia are addressed in the Carers Commissioning Strategy. However, the additional support needs of carers of younger adults with dementia require further consideration.

Improved quality of care for people with dementia in general hospitals

Plans are being developed to identify a specific lead for dementia in general hospitals**.**

Living well with dementia in care homes

Improved professional training relating to dementia is required.

Improved end of life care for people with dementia

There needs to be greater clarity around direction of service provision and multi-agency working.

Recommendations are already being acted upon through the Dementia Partnership Board Group. This multi-agency group is tasked with implementation of the dementia strategy and is specifically targeting the following areas:

- Development of Dementia Peer Support
- Commissioning of Assessment, Care and Treatment Service
- Commissioning of Dementia Care Advisors
- Training for professionals in Dementia Basic Awareness
- Advanced training for professionals
- Improved quality in existing services i.e. memory clinic, Community Mental Health Team etc.

Keeping up the momentum

The 'Living well with dementia in Halton Strategy and Implementation Plan' that accompanies this paper outlines key actions to be undertaken during 2013-2018.

Appendix 1 Later Life and Memory Service Pathway

Halton Later Life and Memory Service Pathway for Professionals. September 2013

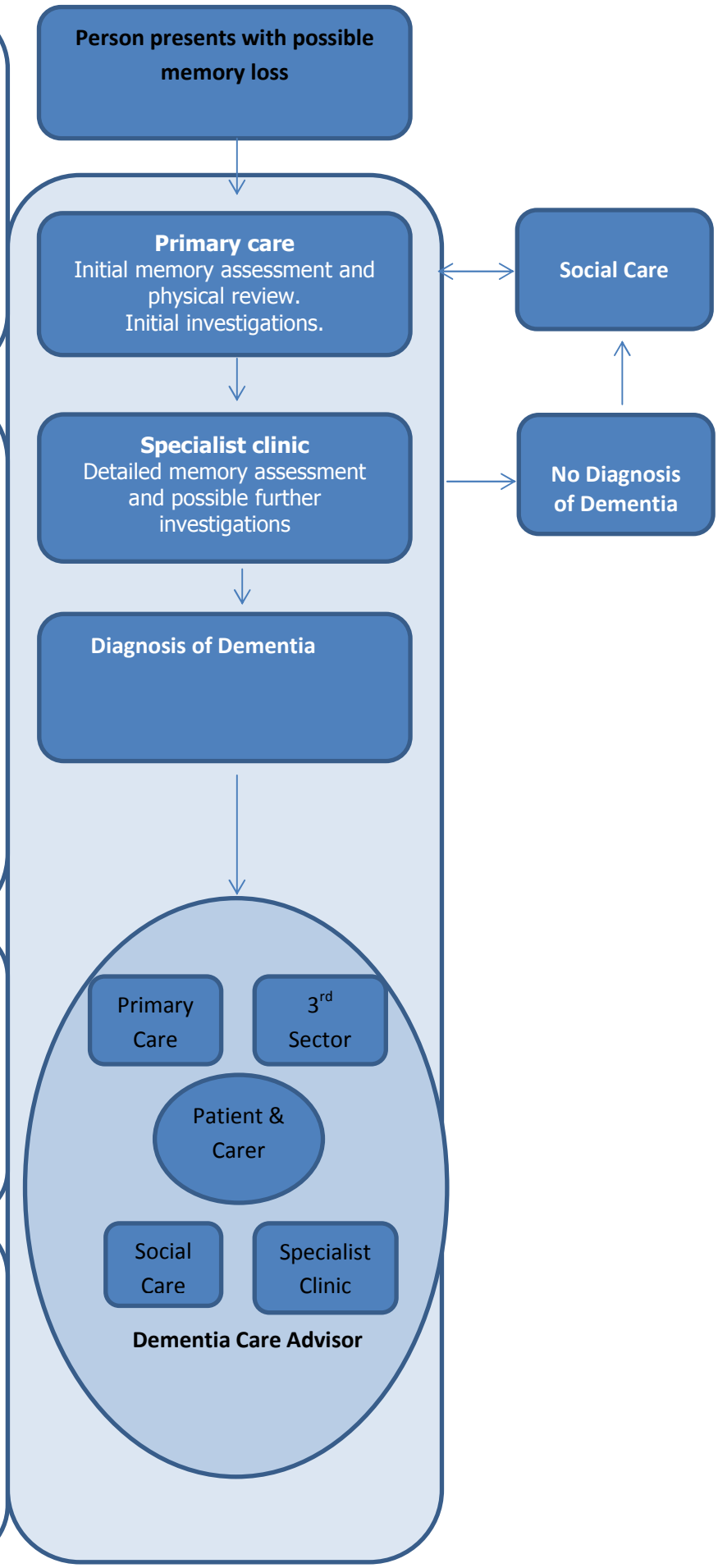
Click here for NICE Pathway for Dementia Diagnosis and Assessment

Patient undertakes '6 CIT' Test (or other). Link to '6 CIT' questions and scoring:http://www.patient.co.uk/doctor/six-item-cognitive-impairment-test-6cit

Routine bloods and ECGPrimary Care Referral to Dementia Care Advisors

Click here for NICE Pathway for Dementia Specialist Assessment

Click here for NICE Pathway for Dementia Diagnosis and Assessment



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