

Wolverhampton City Council

**OPEN DECISION ITEM**

**HEALTH SCRUTINY PANEL**

Date 28 March 2013

Originating Service Group(s) Community

Contact Officer(s)/

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Title

**Developing Dementia Friendly Wolverhampton**

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**RECOMMENDATION**

The Health Scrutiny Panel to note the developments relating to Dementia Friendly Wolverhampton.

## 1.0 **Purpose**

1.1 The Prime Minister has made dementia everybody's business and has issued the following challenge:

*'By 2015, up to 20 cities, towns and villages will have signed up to become more dementia friendly..... Leading national organisations will look at how they and others can play a part in creating a more dementia friendly society and raise awareness on dementia '*

*(Prime Minister's Challenge on Dementia 2012)*

1.2 This Challenge was launched in Wolverhampton at a one day 'Creating Dementia Friendly Communities' conference held at the Science Park on Tuesday 9 October 2012.

1.3 Wolverhampton has signed up to the Dementia Action Alliance and has taken up the Challenge on Dementia laid down by the Prime Minister and aims to create a city where people with dementia are better understood and offered the help and support they need.

## 2.0 **Background**

2.1 In 2009 the Department of Health published Living Well with Dementia: A National Dementia Strategy which aims to ensure that significant improvements are made to dementia services across three key areas: improved awareness, early diagnosis and intervention, and a higher quality of care.

The Joint Dementia Strategy for Wolverhampton clearly reflects many of the key objectives set out in the National Dementia Strategy, NICE quality standard both in terms of outcomes desired by people with dementia and carers. A range of activities are at various stages of implementation. This Strategy prioritises the delivery of five objectives:

1. Good-quality early diagnosis and intervention
2. Improved quality life for people in general hospital
3. Living well with dementia in care homes
4. Reduced use of antipsychotic medication
5. Improved support for carers

2.2 Wolverhampton's Joint Dementia Strategy has a number of person centred outcomes and a detailed implementation plan. This is being delivered through a Joint Dementia Strategy Steering Group which has a multi-disciplinary membership consists of:

- Elected Cabinet Member
- Local Authority/Health Commissioners
- Clinical Commissioning
- The Royal Wolverhampton Hospital Trust
- Consultant Psychiatrist
- Alzheimer's Society
- Service Users and Carers

2.3 In addition there is a sub-group consisting of people with dementia and carers. This group is co-ordinated by the Alzheimer's Society and acts as an advisory capacity for the steering group.

All of the above is driven by Wolverhampton's Joint Dementia Strategy which seeks to achieve the following person centred outcomes:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia and my life
- Those around me and looking after me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life I feel part of a community and I'm inspired to give something back
- I am confident my end of life wishes will be respected
- I can expect a good death

2.4 A number of developments have already taken place in response to the outcomes within the Joint Dementia Strategy:

- Working in partnership with Worcester University, Association of Dementia Studies, a total of 73 dementia care leaders and champions have been developed across the city
- A rolling programme of dementia awareness days have been commissioned for service providers across the City
- Specialist awareness days have been commissioned for commissioners and contract monitoring staff
- A dementia awareness training programme has been delivered to assessment and re-enablement staff, including social workers and occupational therapists
- A specialist dementia ward has been commissioned with an outreach dementia team to work across all wards in the hospital trust
- Alzheimer's Society have been commissioned to deliver 3 Dementia Cafes, including a café for Asian elders
- Service specifications are being revised for all commissioned services in response to the Joint Dementia Strategy outcomes
- A dedicated Resource Centre is commissioned with long and short stay beds day resource

### **3. Prime Ministers Challenge on Dementia**

3.1 The Creating Dementia Friendly Communities conference was a key part of Wolverhampton's bid to become a dementia-friendly city.

3.2 The focus of the conference was to involve and encourage a number of commercial sector companies and religious organisations to do more to help the estimated 3,000 people with dementia in Wolverhampton, a figure which is expected to reach 4,500 by 2030.

3.3 Banks, building societies, shops, churches and temples were invited to take part in this one day conference, which was jointly organised by Wolverhampton City Council and the Association for Dementia Studies at Worcester University.

3.4 The Conference opened with an uplifting Skype message from Christine Bryden who is the author of *Dancing with Dementia*. Christine was diagnosed with dementia in 1995 when she was 46 years of age. Christine's message for everyone at the conference was to:

*'seize every opportunity to make a difference to the lives of people with dementia; seize every opportunity to change the ways in which society labels and stigmatises people with dementia, and seize every opportunity to recognise and value the abilities and contribution that people with dementia can make to their own lives and to society as a whole.'*

3.5 People with dementia and their carers were at the forefront of the day and spoke from the main stage about their lives with dementia, delivering the message that it is possible to lead a fulfilling life with care and support that is both sensitive and flexible. Overall, approximately 200 people attended the conference and debated what needs to be done to improve services in the city.

3.6 Delegates also attended two out of the five workshops available:

- Commercial Businesses
- Learning and Leisure
- Safe Places
- Health and Well-Being
- Dementia Café Live

3.7 The headlines from these workshops are as follows:

- Excellent day, very informative especially listening to people with dementia and their carers about their daily life experiences
- The whole event was real and raw and it was an excellent conference which brought every sectors within the community to work and think about the way forward for the needs of people with dementia
- Informative and delivered at the right level
- Excellent, thought provoking session which has highlighted a number of actions that I will take back to my business
- Thoroughly enjoyed the workshops

3.8 The conference is being made available as a video to view on YouTube.

3.9 A full report evaluating the conference with an executive summary will be submitted to the Joint Dementia Strategy Implementation Group.

3.10 Follow up meetings with commercial sector businesses and religious organisations are being arranged.

3.11 The evaluation and the feedback from the conference will be used to update the Joint Dementia Strategy for Wolverhampton.

#### **4.0 Implementation Plan Headlines – work in progress**

##### **4.1 Evaluation and Value for Money Review of Inpatient/Residential Facilities**

4.2 Community Gateway has been commissioned to undertake an evaluation and value for money review of inpatient/residential provisions for people with dementia across the city. The brief for this evaluation covers the following areas:

- Methodology
- Policy context
- Description of current service
- Market and Value For Money analysis
- Initial assessment of service
- Next Steps

##### **4.3 Mapping of Universal and Preventative Services**

4.4 In addition to the above review, a mapping of universal and preventative services is also being undertaken across the city to include universal services, business, religious and the third sector voluntary organisations.

##### **4.5 Improving Standards in Care Homes**

4.6 Some of the care homes have experienced a high level of concerns relating to safeguarding and quality of care for people with dementia living in their establishments. These concerns have been repeated over the years and the same homes have been subjected to suspension orders and are well known to quality and compliance team, safeguarding and the social work teams.

4.7 The University of Bradford has been commissioned to work with five residential care homes to evaluate practices by the implementation of Dementia Care Mapping (DCM) as a method for improving care practice for people with dementia and will help staff to develop person-centred practice and improve care for residents.

4.8 The first phase has been completed with recommendations allowing care homes to implement the action plan. In the second phase in March/April 2013 another DCM evaluation will take place to check progress.

##### **4.9 Critique and Evaluation of Dementia Care at New Cross Hospital (RWHT)**

4.10 David Sheard from Dementia Care Matters has been commissioned to provide an independent perspective of Ward C22 and a critique of the current evaluation report provided by the University of Worcester. This includes an evaluation of comparative wards at New Cross Hospital and at University Hospital Birmingham.

4.11 Phase 2 will focus on tracking outcomes in relation to a patient sample group following their discharge from Ward C22. This phase will focus on acquiring qualitative data in relation to quality of life subsequently achieved at home.

- 4.12 Phase 3 which will commence in April 2013 is about service evaluation, patient follow-up and outcomes in the community.
- 4.13 Dementia Cafes
- 4.14 The development of Dementia Cafes is recognised as an effective way of delivering peer support services, giving people with dementia an opportunity to share and learn from each other's experiences. This includes for example coping mechanisms in response to the possibility of social isolation; difficulties experienced and overcome in response to diagnosis and the impact of dementia on the day to day lives of people with dementia and their families. Peer support brings with it the emphasis that individuals with dementia and their carers are not alone in coping with the condition and encourages interaction and empathy with others who know as far as is possible about the impact of dementia on daily life.
- 4.15 Further three Dementia Cafes will be running from 1 April 2013 and the total number of cafes across the city will be six. The Dementia Cafes are being provided in partnership with the Alzheimer's Society.
- 4.16 Dementia Opera Project
- 4.17 The arts and particularly music can have a profound effect on people with dementia benefitting their health and well-being in many ways including helping delay the progress of the condition.
- 4.18 Over the next few weeks some 30 people with dementia will be invited to work with a writer, composer and musicians. People with dementia will be writing their own songs which will be brought together in the final performance staged in front of a specially-invited audience of family and friends at the Grand Theatre on 17 April 2013.
- 4.19 Royal Wolverhampton Trust update. See Appendix A
- 5.0 Next Steps**
- 5.1 The implementation plan will be refreshed to reflect the results from the above evaluation reports and the membership of the Joint Dementia Strategy Steering group will be reviewed to reflect the updated commissioning intentions for the next eighteen months
- 6.0 Financial Implications**
- 6.1 There are expected to be broader financial implications from the implementation of the proposals in this report. Such implications cannot be estimated until the proposals have been further developed and will be included in separate reports.
- 6.2 Each project and the implementation plan has a budget and lead organisation identified.  
[MA/19032013/T]
- 7.0 Environmental Implications**
- 7.1 There are not environmental implications for this report.

## **8.0 Equality Implications**

8.1 The aim of developing a Dementia Friendly city is to ensure that significant improvements are made across all service areas which improves the quality of lives of people with dementia and their carers by providing help and support they need throughout the course of the illness, enable them to live lives of the best quality possible.

## **9.0 Legal Implications**

9.1 The Joint Dementia Strategy supports the Council's Social Services functions which are conferred on the Authority under Schedule 1 of the Local Authority Social Services Act 1970. When exercising its Social Services functions the Council is required to act in accordance with directions and guidance of the Secretary of State.

[FD/19032013/E](#)

## **Schedule of Background Papers**

Royal Wolverhampton Trust update	Appendix A
Joint Dementia Strategy	Appendix B
Prime Ministers Challenge on Dementia	Appendix C

## **Background**

The ever growing incidents of Dementia have been well documented in Health and Social Care.

## **Narrative**

The priority for Dementia Care has been elevated through national reports from the Alzheimer's Society, the NHS Operating Framework and more latterly the profile of the Prime Minister's Dementia Group. Wolverhampton Local Authority and The Royal Wolverhampton NHS Trust (RWT) have a track record of prioritising Dementia Care within both organisations and working in partnership to ensure added benefits are realised. RWT completed a two year project, sponsored by the Strategic Health Authority to improve acute care for dementia patients within the acute setting. This project has been possibly elevated in terms of patient outcomes and relative satisfaction levels. However, the evaluation did result in some concerns regarding the challenge placing dementia patients from the acute setting into residential and nursing homes.

## **Dementia Friendly City**

In the past six months the Local Authority and RWT have both hosted important and effective events to raise the profile of the work already in place within Wolverhampton in a move towards Dementia Friendly status and also to agree how best this work can be accelerated. One of the events was attended by Angela Rippon who is becoming a national advocate for Dementia patients and carers, as well as having personal experience herself.

The Chief Executive, David Loughton OBE, was specifically invited to be a member of this multi-disciplinary group and is the only acute Chief Executive within that membership; this is reflective of the priority that has been given to Dementia Care within Wolverhampton. The initial focus for the acute hospital was to ensure a dementia skilled workforce irrespective of role, providing dementia appropriate environments and to provide clinical support where dementia patients receive their care outside of the dementia focussed ward.

The Commissioning for Quality and Innovation (**CQUIN**) payment framework is a measure that is used to drive improvements in certain quality areas. RWT has been well placed through its previous dementia work to fully achieve the national dementia CQUINN target for 2014. Attached is an overview action plan and progress against the target dates. Part of the response to the CQUIN has been the investment into the Carers Support Group; this group is facilitated by the Trust's Dementia Outreach Team and a volunteer carer under the voluntary staff members. Specialist support is frequently provided for the sessions from Speech and Language Therapy (SALT), dieticians, chiropody, outside services omega, Penn Hospital Older Adults, Occupational Therapists and Healthy Minds. The purpose of this group is to provide support and information to empower and skill carers for those who are living with dementia. The group recognised the contribution it can make to reducing delayed discharges and reducing multiple admissions in the future. The group also recognises the opportunity to enhance multi-disciplinary working and building relationships with community services. The support group are able to sign-post carers to services available within the community and Local Authority.

## **Future Aims of the Dementia programme**

- The role out of dementia knowledge and skills needs to be strengthened to ensure that every member of staff is able to interact with dementia patients and their carers effectively



- A focus within the emergency portals to review admission pathways to facilitate best practice for dementia patients
- Harness dementia friendly philosophy for all patients within RWT settings, which results in personalised care
- Strengthen the model of community care to enable dementia patients to receive care in their residential settings rather than the disruption of hospital site visits

### **Summary**

A lot of work and progress has taken place over the past two to three years in both the Local Authority and Health Care settings regarding dementia care. The burden of dementia care is ever increasing for both social and health services and progressing this work is not optional, but essential if organisations are to provide effective care and support.

Good relationships exist between the Local Authority and Health Care and this will enable further progress, and result in the Dementia Friendly City being achieved effectively in a timely manner.

Cheryl Etches  
Royal Wolverhampton Trust

## OVERVIEW ACTION PLAN

### Area of innovation

Carers of people with dementia

### Criteria for providers

Demonstrate that plans have been put in place to ensure that for every person who is admitted to hospital where there is a diagnosis of dementia, their carer is sign – posted to relevant advice and receives relevant information to help and support them.

### Local commissioner assurance

Assure that provider plans are in line with local commissioning strategy and 2013/14 national dementia CQUIN

### Action Plan

<b>Objective</b>	<b>Action</b>	<b>Lead Person</b>	<b>Target date</b>
For carers to have access to a member of a specialist dementia service	<ul style="list-style-type: none"><li>• Outreach teams contact details given to families and carers of all patients actively or proactively referred to the dementia outreach service throughout the Hospital.</li><li>• Promotion of dementia services within all departments of New Cross Hospital with tailored training sessions, posters, leaflets and role modelling care delivery.</li><li>• Promotion of dementia services at New Cross Hospital within public groups such as Alz Cafes and support groups through Carer Support Group and family liaison</li><li>• Promotion of dementia services at New Cross Hospital within relevant services e.g. community MH teams, Alzheimer’s society, nursing and</li></ul>	Julie Willoughby	Action in place and ongoing

	residential homes		
For carers to be signposted or referred to appropriate community services	<ul style="list-style-type: none"> <li>• For the outreach team to meet with and discuss the needs and concerns of the carer to identify any issues in the community</li> <li>• Where appropriate, for the outreach team to signpost carers to relevant community groups e.g. Alzheimer's society, Admiral nurses, carer's support, Dementia UK, Crossroads, support groups</li> <li>• Where appropriate, for the outreach team to refer carers to relevant community groups e.g. as above</li> </ul>	Gemma Hammond	Action in place and ongoing
For carers to have access to information on support and services relevant to dementia care in their local area	<ul style="list-style-type: none"> <li>• Information leaflets available in public areas on support and services relevant to dementia care available</li> <li>• Carers support display offering practical advice, information and publicising relevant services on C22</li> <li>• Carers support group at New Cross Hospital run by carers and healthcare professionals, accessible to all carers of patients living with dementia offering a forum for carers to meet other carers, speak with professionals and be signposted to relevant services within their local area.</li> </ul>	Gemma Hammond	Action in place and ongoing

# A Joint Dementia Strategy for Wolverhampton



*Foreword*

These are challenging times for the public sector and dementia is one of the biggest health and social care challenges of the present day, with the numbers of people with dementia living in Wolverhampton expected to grow by 45% over the next twenty years. It is only through joint working that we can provide better health and social care outcomes for people with dementia and, responding to this challenge, Wolverhampton City Council and NHS Wolverhampton have co-produced this Joint Dementia Strategy with a wide range of stakeholders, including people with dementia.

This strategy adopts a person centred value base that recognises people with dementia as **people** first and foremost. This recognition means delivering a health and social care response that respects individuality, maintains dignity and offers a quality and range of choices in order to support independent living. Most of all, this strategy recognises that all people with dementia have exactly the same rights as everyone else to lead healthy, happy and fulfilling lives.

This Joint Dementia Strategy, then, truly strives to ensure that people do indeed live well with dementia.

### **Introduction**

This joint dementia strategy delivers the local response to the National Dementia Strategy and will operate as a framework to enable all stakeholders to work in partnership to ensure the delivery of improved quality of life outcomes for people with dementia living in Wolverhampton.

This joint dementia strategy is driven by the following vision:

***‘To enable people with dementia in Wolverhampton to live well and have maximum choice and control over their lives by ensuring that all services are person centred, culturally appropriate and able to recognise and deliver the many factors that contribute to good health and positive well being.’***

This joint dementia strategy will ensure that people living with dementia in Wolverhampton are able to say:

- *I was diagnosed early*
- *I understand, so I make good decisions and provide for future decision making*
- *I get the treatment and support which are best for my dementia and my life*
- *Those around me and looking after me are well supported*
- *I am treated with dignity and respect*
- *I know what I can do to help myself and who else can help me*
- *I can enjoy life I feel part of a community and I'm inspired to give something back*
- *I am confident my end of life wishes will be respected*
- *I can expect a good death*

Whilst recognising that living with dementia brings different challenges to older age, this joint dementia strategy also adopts the values expressed in Wolverhampton's Dementia Forward Plan:

1. No-one will be discriminated against
2. Every older person will be recognised as a valued member of the community

3. Each older person will be respected as an individual
4. Services will maintain and enhance dignity, self esteem, privacy and independence
5. Services, opportunities and facilities will be accessible
6. Older people will contribute to the design and planning of services
7. Services will be high quality, flexible and responsive to individual need
8. Services will be delivered in partnership and incorporate the needs and wishes of older people

All of these values will be delivered for people with dementia living in Wolverhampton.

The starting point for this joint dementia strategy is to offer a definition of dementia.

### ***What is Dementia?***

Dementia is an umbrella term used to describe a number of different dementia type symptoms. The following are the main types of dementia:

- *Alzheimer's Disease*
- *Vascular Dementia*
- *Dementia with Lewy bodies*

The prevalence of dementia increases with age.

All dementias produce a decline in a person's cognitive (intellectual) abilities, affecting memory, language, understanding, reasoning, problem solving, and concentration, but each person's dementia is unique and will impact on individual lives in very different ways.

Whilst it is less common, there is an increase in early onset dementia - people under 65 years with dementia. 50% of people with Down's syndrome aged 60-69 and 22% of those over 60 with other learning disabilities are now recognised to be at risk.

The length of time a person has dementia symptoms varies.

Dementia makes demands on families, local support networks and communities, and services supporting the person with dementia need to be flexible and responsive to the very individual needs being presented.

### ***Person Centred Approach***

Tom Kitwood (1997) pioneered a new culture approach to dementia care and developed an enriched model of support that moved the focus away from the neurological impairment (brain damage) and back on the person. Kitwood emphasised the need to consider and protect all of the things that make every person, including people with dementia, unique human beings:

- Personality
- Biography
- Social Psychology
- Health
- Fitness

These are described as the things that enrich everyone's life and also represent the elements that need to be supported in order to retain a healthy, positive well being for people with dementia. This new culture approach has led to the development of person centred approaches to dementia care.

This person centred approach model has been developed further elaboration and adopted by the Department of Health. This model is known as the as the VIPS model (Brooker 2007) and can be summarised as:

- V** A value base that asserts the absolute value of all human lives
- I** An individualised approach, recognising uniqueness
- P** Understanding the world from the perspective of the service user
- S** Promotion of a positive social psychology in which the person living with dementia can experience relative well-being

This person-centred value base is adopted by Wolverhampton's Joint Dementia Strategy.

### ***What are the key drivers for change?***

#### ***Demographic Growth***

In the UK:

- There are about 750,000 people with dementia
- The number of people with dementia is expected to double in the next 30 years
- The estimated costs of care in England will rise from £14.8 billion in 2007 to £34.8 billion by 2026, a rise of 135% (Kings Fund, 2008)
- Dementia costs the health and social care economy more than cancer, heart disease and stroke combined (Lowin et al, 2001)
- About 13% of people in England die with dementia (Dementia UK, 2007)
- Dementia is particularly prevalent in the population aged 65 years and over. Although there are people younger than 65 years with dementia and therefore services cannot be limited to older adults.
- People with a learning disability are living longer and are more at risk of developing dementia.

In Wolverhampton:

- The estimated number of people living with dementia in Wolverhampton was 2,940 people (POPPI 2010), which is approximately 7.3% of Wolverhampton's older person population
- The number of people with dementia is expected to increase by approximately 44%, over the next 20 years to 4,430 people. This represents an increase of approximately 75 people per year.
- The number of people over 85+ is projected to increase by over 85% over the next twenty years (POPPI 2010). This is significant because the prevalence of dementia

increases with age and the older age group are more likely to have other illnesses and require more complex care.

- Around 25% of older people are living in lone households (POPPI 2010). It is difficult to predict how this will change over the next 20 years, but it is suggested this will increase to 26%, 13515 people, (POPPI 2010)
- There is considerable under diagnosis of dementia. About 40% of the people with dementia in Wolverhampton are on a GP dementia register.
- The number of older people from BME communities is projected to increase. It is estimated that BME groups will comprise 1/3 of the Wolverhampton population by 2026 (Joint Strategic Needs Assessment 2008, page 19) with the biggest increase in people from mixed ethnic background
- 7% of the older population are Asian elders (POPPI 2010)
- It is predicted that the number of people diagnosed with an early onset dementia is underestimated by three times (Dementia UK 2007)
- There is incomplete information regarding Alcohol-related dementia. This is considered to be under-recognised and may account for up to 10% of all dementia cases –around 70,000 people in the UK. (British Journal of Psychiatry).
- Over 6,000 of those people who identified themselves as carers said that they were providing 50 or more hours each week

### **National Policy Guidance**

**The National Dementia Strategy (NDS)**, Living Well with Dementia, launched in 2009, sets out a five year plan to achieve its vision of enabling people to live well with dementia which has seventeen objectives (see Appendix Two). The Strategy articulates an overarching ambition to develop high quality services for everyone with dementia, regardless of age, ethnic group, social status, the stage of their condition or where they are in the health and social care system.

As already described, this joint strategy delivers a response to four of the priority areas identified in the National Dementia Strategy (2009):

1. **Good quality early diagnosis and intervention for all:** *Key driver examples* - Out of the 3000 people with dementia living in Wolverhampton only 40% are formally diagnosed (2010); nationally only a third of GPs feel they have adequate training in diagnosis of dementia (National Audit Office 2010)
2. **Improved quality of care in general hospitals:** *Key driver examples* - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co morbidity with general medical conditions is high; people with dementia stay longer in hospital, have poorer quality outcomes and one third of people with dementia admitted to hospital never return home (Alzheimer's Society, 2009).
3. **Living well with dementia in care homes:** *Key driver examples* - Two thirds of people in care homes have dementia; 45% have moderate or severe cognitive impairment; 40% are not in specialist dementia care beds that are appropriately resourced and have a well informed and trained workforce (CSCI, 2008); behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs; living in a care home is often an everyday reality of life for people with dementia, with one third (244,000) residing in care homes (Alzheimer's Society, 2007) and dementia cited as being the strongest determinant of entry into



residential care (Alzheimer's Society 2008) and the reported experience of living in a care home for some people with dementia is very poor (Alzheimer's Society, 2008 and BBC Production, 2009 are good examples) with the protection of dignity going unrecognised, respect for independence, choice and control ignored, and even the right to personhood denied.

4. **Reduced use of antipsychotic medication:** *Key driver examples* - Antipsychotics are a tranquilising medication primarily used to manage psychosis (including delusions, hallucinations as well as disordered thought). Nationally there are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of this prescription. Audits in Wolverhampton suggest that prescribing appears low compared to other PCTs locally, but further work is needed to improve prescribing in line with national recommendations. Being in hospital or a care home for people with dementia increases the risk that antipsychotic drugs will be used. The current usage levels pose an increased risk of death and stroke (Clinical Knowledge Summaries, June 2010) and nationally evidence suggests that there is insufficient awareness amongst GPs to help them diagnose and manage dementia (The National Audit Office (January 2010)).

In a general sense, the improvement of community personal support services is integral to and underpins each of the four priorities as it supports early intervention; prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay:

- The Forget Me Not report in 2000 (revisited in 2002) identified a number of detrimental factors impacting on the lives of people with dementia: for example, the perennial lack of clear information and advice was identified as was the paucity of counselling and advocacy support for people with dementia and carers.
- The Forget Me Not report also criticised the lack of specialist domiciliary care services, the incomplete assessments of need and the lack of joint planning between statutory agencies (Audit Commission 2000 & 2002). All of this was followed up by a National Audit Review (National Audit Office, 2007 – updated 2010) of dementia services, which reached the same conclusions and raised the same concerns around early diagnosis, lack of support for carers and the general quality of care and support available for people with dementia. The review concludes that people with dementia are not being served well and that the services provided for people with dementia and their families were not offering value for money (National Audit Office, 2007 & 2010).
- In a national survey of 1000 GPs 47% of GPs said they had sufficient training to diagnose and manage dementia; 58% said they felt confident about giving advice about management of dementia-like symptoms (National Audit Office, 2010). From a local perspective, only 38% of people with dementia are identified on a GP dementia register - there are currently an estimated 2000 people with dementia not on a GP dementia register and there is significant variation across GP practices.

***Think Local, Act Personal (January 2011)*** is a sector wide statement of intent that makes the link between central government's vision for social care and Putting People First (Department of Health, 2007). Putting People First is a shared concordat signed off by a number of government departments that sets out the vision for the transformation of public services. As part of this vision, Wolverhampton has developed a Citizen's Journey,

incorporating a Customer Pathway (see Appendices Three). This demands a more personalised; person centred approach for all citizens, including people with dementia, which delivers:

- A real choice of a range of high quality universal, preventative Services that are accessible and fit for purpose, and a real choice over who provides services and proper control over what, when and how services are delivered.
- A real choice of high quality targeted services that delivery an appropriate and timely response for people with dementia, including re-enablement services and crisis support to enable people with dementia to remain living independently within their own homes
- Accessible self-assessment; care and support planning and individual (personal) budget formats and the provision of high quality, accessible information and advice across a range of areas that is consistent and enables people with dementia to live better lives.

### ***Reablement & Prevention***

Given the context of a 26% contraction of public sector budgets over the next four years, there are some clear demographic challenges facing councils and the NHS, which can be summarised as more people to serve with less money. One of the ways in which the public sector is responding to this challenge and the needs of people with dementia is by expanding the range and availability of reablement and prevention opportunities, increasing the likelihood of independent living being retained or regained whilst at the same time delivering positive quality of life outcomes and reducing the demand on the public purse. Increasing demographic and expectation demands in a time of public sector funding austerity means that the potential offered by reablement and prevention to decrease the take up of publically funded services and deliver positive outcomes for service users is a highly attractive commodity.

All of the national research so far shows or implies that domiciliary reablement in particular can deliver significant improvements in service outcomes:

- Reablement intervention achieves cost savings by reducing or removing the need for ongoing home care support - but it does require significant initial investment
- Reablement intervention improves a range of quality of life outcomes – particularly in relation to restoring independence and restoring activities of daily living

The adoption of a reablement and prevention philosophy and approach also increases the likelihood of the following outcomes being delivered:

- The avoidance of unnecessary hospital admissions
- The opportunities for earlier hospital discharge
- The delivery of independent living discharge route from hospitals: home rather than care home

- The reduction of readmission rates following in-patient treatment
- The general opportunities to enable healthy living and positive well being

All of these developments will be taken forward as part of this strategy and will inform the action plan developments designed to improve the lives of people with dementia.

### ***Improved Support for Carers***

In June 2008 the Department of Health published the National Carers Strategy. This strategy sets out the Government's vision for carers and identifies a series of outcomes to be achieved by 2018 for all carers:

- Carers will be respected as expert care partners and will have access to the integrated personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

The Wolverhampton Carers' Strategy sets out a vision for carer services in Wolverhampton over the next three years based around the outcomes of the National Carers' Strategy. Unpaid informal carers are the main providers of care in the community and their contribution is significant in supporting Health and Social Care services. The stability of services is reliant on the willingness of carers and their ability to continue caring. Two thirds of people with dementia live in their own homes and most people want to remain living in their own homes for as long as possible. Most family carers want to be able to provide support to help the person with dementia stay at home but they sometimes need more assistance than is currently routinely available. Being a carer can play a big part in the lives of older people. The 2006 Older Peoples' Strategy identifies over 12000 older people living in Wolverhampton who have caring responsibilities and cites the 2001 census data as identifying older carers as more likely to be providing high levels of care (50+ hours of unpaid care each week). A number of these carers will be providing support for people with dementia.

Commissioners will make the necessary links with the proposals and developments that emerge from the local carers' strategy and will include carers as part of their local needs analysis in order to better understand this crucial area from the perspective of people with dementia.

### ***Value for Money***

Given the current economic climate and the budget pressures facing all public sector services, the development of a joint dementia strategy will have to take into account the need for all services to deliver value for money.

An Alzheimer's Society Report in 2007 estimated the annual cost of dementia for the United Kingdom at more than £17 billion, or £25,000 per person (Alzheimer's Society 2007). A more recent study carried out by the Alzheimer's Research Trust (ART, 2010) puts the number of patients with dementia in the United Kingdom as 821,884 – 37% of

these in long-term care institutions – and estimates the cost to the United Kingdom's economy as being £23 billion pounds per year, including health, social care, informal care and productivity losses (ART, 2010). Applying these figures to Wolverhampton gives a total annual cost of dementia to the Wolverhampton economy of £75 million pounds (3000 people X £25,000 per person). The Kings Fund predicts that the cost of dementia alone in England will rise to £34.8 billion by 2026 (Kings Fund 2008).

The adoption of a value for money approach is not just about cost. The expectations of service users are increasing and likely to become more challenging as greater choice is delivered through the roll out of personal budgets, and there are also examples of duplication and waste across the health and social care economy – which results in a poorer quality customer experience. This joint strategy, then, will take into account a wide range of value for money aspects, including the following:

- Increased opportunities for joint and generic working
- Improved quality of services to agreed standards
- Increased range of providers, offering greater choice of services
- Establishing the true cost of care
- The shift of resources away from critical, acute services and towards universal prevention services
- Increased opportunities for self care and self directed support

At present the majority of the budget for health and social care for people with dementia is spent on hospitals and care homes. In most cases, these service options currently deliver poorer quality outcomes for people with dementia and, given the high costs of dementia and the human cost of failing to provide good quality care, service commissioners and planners must treat these as a priority area for improving and delivering cost effective dementia services.

Avoiding unnecessary admissions to care homes and hospitals, then, will play a critical part in achieving the outcomes identified in this strategy. In order to reduce early entry to residential care and reduce unnecessary hospital admissions, there is a need to develop early intervention and prevention responses and, with an increasing number of people with dementia, a need to shift the emphasis of care to improve community provision. The health and social care system must work in partnership to improve the efficiency and quality of dementia services (All Party Parliamentary Group on Dementia, 2011; DH 2010). Finally, the adoption of a reablement and preventative philosophy and approach is also essential to the achievement of a radical shift of resources away from traditional service provision to independent living outcomes across the dementia pathway. This means delivering a total system and culture change so that reablement and prevention become 'what we do around here' or business as usual.

In summary, for both health and social care there are a range of financial challenges that can be identified and which need to be addressed as part of this joint dementia strategy:

- Existing patterns of spend continue to be driven by service provision
- Traditional responses continue to perpetuate and consume long term expenditure
- Because of demographic and economic drivers this position is not sustainable
- Investment in the development and delivery of a reablement philosophy and approach is a critical element of shifting resources from acute/specialist care to prevention and supported self-care maximise which promotes independent living opportunities

All of these challenges will drive the design and content of the joint dementia strategy action plan and, as part of a market shaping strategy, all services will be subjected to a value for money review. As part of an implementation plan, the resulting joint dementia strategy will have at its core a comprehensive financial strategy.

### ***What have we done so far?***

This section will deliver an update on some of the key developments that have taken place so far in response to the National Dementia Strategy. Where possible these will be described under the each of the four priority objectives.

#### ***1. Good quality early diagnosis and intervention for all:***

- A co-ordinated training programme has commenced across all sectors, including hospitals, primary care services, health and social care community based services and care homes. This training has concentrated on improving the awareness and understanding of dementia, person centred approaches, options and treatments, and the role of carers and support opportunities. All of the training elements have emphasised the importance of early diagnosis and intervention.
- A baseline map of people with dementia in Wolverhampton has commenced, including GP dementia registers, a review of the social care client information data base and a review of patients admitted to the local general hospitals to identify the actual diagnosed rate against prevalence. In addition, the Mental Health Trust have started identifying all users of services according to clusters, which enables people with dementia to be identified as a distinct group. All of these measures indicate that there is a significant under diagnosis and recording of people with dementia.
- Wolverhampton already has a well established specialist memory service which offers diagnosis, assessment, early treatment, interventions, ongoing care and support and signposting to people with dementia of all ages and their carers. There is an ongoing review of this service which has included a revision of the referral pathway to ensure timely access to assessment and appropriate intervention. This has led to a number of improvements being identified which are in the process of being implemented. Additional investment has been made in services in 2011.
- Royal Wolverhampton Hospital Trust is proactively identifying people with dementia or dementia like symptoms on admission to hospital. This information is shared with their GP on discharge, so the person may be offered full assessment and support.
- Wolverhampton City PCT has introduced a new system to improve care for people with dementia who take dementia medication. This 'shared care' will mean that patients will be able to obtain their medication and check-ups more easily.

#### ***2. Improved Quality of Care in General Hospitals***

A new model of care has been developed at the local general hospital which includes the following:

- A dedicated and redesigned ward for people with dementia
- An enhanced training and development programme
- A person centered and outcomes approach to care: 'A Care Bundle'

- An in-reach service to advise and support all parts of the hospital
- An enhanced level of staff and the inclusion of trained volunteers

Additionally, a mental health liaison service is available in the hospital to offer advice and information to staff on all the wards regarding dementia.

### **3. Improved Quality of Care in Care Homes**

Worcester University has delivered two modules to managers and front line care staff across all service areas, including care home providers, and worked with commissioners to improve local service standards for people with dementia. This work has achieved the following:

- Improved knowledge and awareness of person centered approaches to care and support
- The development and identification of dementia care champions
- The development and identification of dementia care leaders
- Improved service specifications and contract monitoring arrangements

### **4. Reduction in Anti-Psychotic Medication**

A joint working group has been established (including the West Midlands advisor re prescribing in dementia, and representatives from the local area).

- A joint action plan to address the recommendations of the 'Time for Action' (2009) report has been developed.
- Audits have been completed to understand local use of antipsychotics.
- GPs have received updates regarding safe prescribing of antipsychotics.
- A range of education sessions have been delivered for GPs, including a Dementia Study Day with attendance of 120 people.

### **5. Additional Actions**

- The Dementia Forward Plan, which focuses on the social care aspects of the National Dementia Strategy, was launched on the 01 October 2010. This Forward Plan has a range of outcomes and developments which will form a social care commissioning work plan for the next eighteen months.
- A specialist end of life support team is now focusing on improving the service for people with dementia. This specialist nursing team works closely with services across the city, offering skilled holistic assessment and care, advice and education for a range of teams, including hospital staff members, GPs, Community Mental Health Teams, Community Health Teams and care homes.
- A contractual agreement has been reached with the Alzheimer's Society to provide three Dementia Cafés, including one café for Asian elders. All three Dementia Cafes are now in operation one based at Bantock Park, the second in the local art

gallery, and the third operating from Blakenhall Healthy Living Centre which is specifically for people who speaks the Asian languages.

### ***Co-production: What did the consultation tell us?***

In order to co-produce the joint dementia strategy, a public consultation was completed between May and August 2011. Over 300 people attended workshops over the three month period and the consultation was also taken to the Mander Centre and the City Show where large numbers of people got involved. Information stands were also left at venues throughout Wolverhampton along with feedback forms and pre paid envelopes inviting people to comment. Twenty four written responses were received.

A copy of the full consultation feedback is available on request.

Through the series of workshops and consultation events, a wide range of stakeholders, including people with dementia, expressed their views and delivered their perspective on the development priorities for the five priority outcomes:

1. Good-quality early diagnosis and intervention
2. Improved quality of life for people in general hospitals
3. Living well with dementia in care homes
4. Reduced use of antipsychotic medication
5. Improved support for Carers

The following information was themed from the comprehensive notes collated during the three month consultation process.

#### **Good Quality Early Diagnosis and Intervention:**

There was general consensus that good quality early diagnosis and early intervention is vital to ensure that people with dementia have the opportunity to access medication and services as early as possible. GP's were said to not always take problems seriously and often say that symptoms are due to old age rather than developing dementia. Also patients visit the GP late in their illness as they also see memory problems as a problem associated with the ageing process. This can lead to delays in getting a correct diagnosis and delay treatment. Lack of GP training and awareness was identified as an area of concern and it was said that we should have more specialist GPs.

An education programme was said to be needed particularly within BME communities to ensure that people understand what dementia is and to ensure a reduction in the stigma that might be attached. GP practises should have a good knowledge of their practice population and create a register of people with dementia and their carers, highlighting the diagnosis on notes to ensure all practise staff are aware that someone has dementia or is caring for someone with dementia. Extra dementia monitoring mechanisms were said to be needed in general practice.

Early diagnosis was thought to be difficult due to long waiting lists, vulnerable people need early support as there is often a lapse between diagnostic concerns and diagnosis and people are often scared of a diagnosis of dementia and need support systems in place to ensure that they have all of the information that they need. Once tests have been carried out, consultants need to be clear on the process post diagnosis and ensure that people

are aware of what services are available to them. Clear easy guidelines for the public would be helpful with a clear explanation to the patient about what is going to happen and what is to be expected. A directory to signpost people to services and to understand pathways is needed.

### **Improved quality of life for people in general hospital**

There is a need to look at the point of entry to hospital services: Most GP or Accident and Emergency (A&E) admissions are not for the dementia but for physical issues. Often hospital is seen as the 'safest' place to put someone but we need to prevent that admission in the first place. A&E is often the first point of contact and the human touch can get lost, If someone has 'challenging behaviour' admission through A&E can make matters worse, families and carers should be allowed to accompany patients into the assessment area rather than being left to register them and sit in the waiting area. Full medicals should include being checked for dementia, and should be carried out at initial assessment either in A&E or Emergency Assessment Unit (EAU). Older people should be given an 'overhaul' and not just be treated for an illness or fall.

General wards are not geared to looking after patients with dementia. The workforce needs skills and training in dementia to ensure that members of staff are able to support the individual. Hospital training programmes should be for the whole staff team, and should be ongoing and monitored to identify effectiveness - more well trained staff are needed to recognise and manage patient behaviour and staff need to be able to recognise that people may have dementia as well as physical problems. A better skills mix is needed on wards, general and mental health nurses should be mixed together, and more dual qualified staff should be available. All staff should be trained in dementia awareness - including domestic and security staff. Carers are often excluded and they should be enabled to work with staff, and staff trained to make sure carers are involved.

There should be additional auxiliary nurses/ health care assistants in general wards trained to deal with dementia patients as they have more time to spend with the patient. Having one key person/a named nurse to ask questions of is very helpful for carers and family members. Hospital staff should ensure that they have sufficient information to support patients who have been transferred from the community or care home. They need to know the history of the patient and often care homes staff views are disregarded. Most general hospitals have different systems in place which is often chaotic. There is a need to develop outreach from D22 and spread its work to the rest of the hospital. More than one specialist ward was felt to be needed.

Older people's wards are different to young peoples, there is lots to do on younger peoples wards perhaps we should adopt elements of that, perhaps by using more volunteers. There should be support for carers to be allowed to stay overnight in the same way that they do for young people. Activities are needed on the ward to ensure people are kept occupied. Hospital can be very boring and can be worse for people with dementia. Table space where people with dementia can eat together and encourage each other is an excellent idea, it should be recognised that dementia patients have special needs. There should be more support structures in place for when people leave hospital. Wards should consider where people might go after discharge at a much earlier stage in their care as people with dementia stay longer than most, often because you can't get a quick enough care package organised.



More community based services are needed, with skilled dementia nurses in the community mental health team (CMHT) alongside outreach teams from dementia services - this would help to prevent admission and keep people at home. Outreach and support at home services are needed to keep people at home for as long as possible. Some patients admitted to hospital unnecessarily could have complex social issues which could be treated in the community. Enough step up, step down beds and more respite care is needed. Consultants should have an urgent pathway to the brokerage team. A team in A & E who are able to prevent inappropriate admissions and treatments would be welcomed.

### **Reduced use of antipsychotic medication**

When medication is used regular reviews are needed to make sure it is still needed and to manage side effects. Trained carers are needed to help with medication some medication should only be given when needed - when challenging" behaviour is presented. Medication is sometimes used to keep patients 'safe' a better environment for patients may help reduce the need for medication to be used in this way. Low staffing levels lead to medication being used to 'quieten' patients. This should not be allowed and there should be sufficient staff to help people with dementia to stay calm; trained staff to handle behaviour and use other techniques to calm them. Managers should recognise that it takes longer to work with someone with dementia to ensure that they are safe and well looked after.

When medication is prescribed there should be regular checks, patients should be monitored and taken off medication when it is no longer needed. Better information should be given to patients and carers about medication and alternatives available.

### **Living well with dementia in care homes**

Anyone who works in a care home should be trained and should have a good understanding about dementia and they should see the person first and treat them with dignity, confidentiality and respect. Caring was said to be unrecognised as a career and is not well paid; staff should be highly trained and paid for that. There should be good terms and conditions which in turn will raise standards. There should be no 'descriptive' staffing ratio it should be the most appropriate number for the people within the care home.

Residents should be in a person centred environment. And dementia awareness training should be provided for all staff including leaders and managers. Staff members are often trained by the cascade method and this doesn't always work and training can become diluted. Staff training is needed to help them deal with dementia patients and this should include calming activities and tactics, particularly when patients are aggressive to ensure medication is not given to keep people calm. Care homes can sometimes have rigid processes that do not allow staff to take extra time to give attention to individual patient's needs; they should talk to residents during personal care tasks not to each other. A key worker system should always be in place.

Care homes should encourage people to move around and exercise and try to get them outside into the gardens. Regular access to dentist, opticians and chiropody should be available. Homes should be located within pleasant surroundings, environments that stimulate senses - colour, sound, touch. In one of the workshops, a person with dementia said "I would want the home to be traditional and comfortable like my own home is and would want a comfortable chair, I don't want huge lounges, I do want comfy furniture and

foot stools and would like my own room with en suite facilities, I don't want to share bathrooms".

A full and appropriate activities programme should be available, including; music, swimming, exercise, singing, interaction, libraries, outings, shopping assistance, walks, etc. Get community groups involved, school children, visiting care homes; this can help the patient and the visitor and can help to reduce the stigma of dementia patients across the wider community. Use volunteers, value them and reward them, not necessarily with money.

Research is needed on the impact of nutrition (food and drink) on the brain and its long term affects; we know alcohol has long term effects, so could other food/drink. Care homes should offer good healthy nutritious diets with a good choice of menu with regular mealtimes. Homes shouldn't be forewarned before inspection and could have a 'trip advisor' type website where families can recommend good care.

### **Improved Support for Carers**

GP's should receive training to recognise symptoms of dementia at an early stage and should welcome the input from family carers. Carers often feel disempowered and under valued by the medical profession and they feel that there is so much more that they could input into the correct diagnosis if they were listened to more. Carers and family are key sources of information, GP's need to listen to what the family is saying. Better information and awareness is needed by GPs about support services for patients and carers. Lack of support has an impact on the health of the carer, the doctor cares for the patient but there should be a whole family approach. Health needs of carers should always be considered.

Carers feel that there is a lack of communication and information available to them and they would like to see a workable single point of access with a good referral pathway and would like to have information about appropriate support in a timely fashion. They would like a telephone helpline available to them that they could access and ask for information and support particularly about the progression of the dementia and a check list or information pack provided for carers. Knowing what is likely to happen could help carer's prepare and be able to give more support to the person they care for.

Difficulties were expressed regarding care plans; when a change is made to a care plan a new assessment is needed. Different services use a mixture of paper and electronic systems. Documents have to be sent by post and the system manually updated causing a delay in the actions identified in the care plan being undertaken. The lack of communication between services makes it difficult for patients and carers to understand the processes and is a lost opportunity for the services to learn from each other about the experiences with the patient/service user.

Carers need more breaks from their caring role; more dementia cafes which allow for peer support and information and gives them the opportunity to socialise with the person they look after. Day care facilities continue to be needed as this allows a break for both the carer and the cared for. Carer's would also like to see some support at night to enable them to get a decent rest to enable them to cope better during the day. Day care facilities/respite care can help a carer maintain their normal routine ie going to work which allows the dementia patient to live at home and also gives the carer opportunities to live, earn, progress, etc. If a carer has to give up their job due to their caring role they will be disadvantaged in the future.

Carers found that being in touch with a key worker significantly helped them improve conditions for the patient and helped the carer to cope.

More advocacy services were said to be needed for both the person with dementia and their carer. A care co-ordinator for carers / patients and a key worker is needed, where you can get information and assistance about caring. Families need more information about dementia and we need to reduce the stigma that can still be attached to this illness. Far more awareness is needed for all members of society possibly through a media awareness campaign to encourage acceptance and understanding of dementia.

Better information about equipment should be available to help care for people who also have physical ailments, e.g. pressure pads and equipment. Better information on benefits that you are allowed i.e. attendance allowance and support to help make a claim.

***What developments will we take forward?***

An Action Plan will be regularly reviewed and updated and closely monitored through a multi agency steering group which will have a clearly defined governance arrangement. This, in turn, will be updated in response to the various developments that are currently emerging across health and social care.

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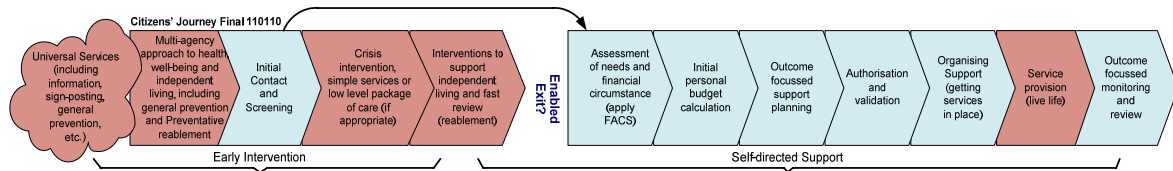


## Appendix One

### National Dementia Strategy – Seventeen Objectives

Objectives	Area Lead
1. Improved Public & Professional Awareness	All
2. Good Quality Early Diagnosis and Intervention	Health
3. Good Quality Information for people with Dementia and Carers	All
4. Easy Access to Care and Support	All
5. Structured Peer Support and Learning Networks	All
6. Community Personal Support	Social Care
7. Carers Strategy	Social Care/All
8. Good Quality Care in Hospitals	Health
9. Intermediate Care	Health/All
10. Housing and Telecare	Social Care
11. High Quality Services in Care Homes	Social Care
12. Good End of Life Care	All
13. An Informed and Effective Workforce	All
14. Joint Commissioning Strategy	All
15. Better Regulation and Assessment	All
16. Review of Research	All
17. National and Regional Implementation	All

**Citizens' Journey – Putting People First**



	<p>Block 1: Universal services are the general support services that are available locally to everyone, such as transport, leisure, education, health, housing, community safety and access to information and advice.</p>
	<p>Block 2: Services to help Citizens stay healthy and live independently; general prevention, targeted at areas of concern; e.g. obesity and secondary prevention, targeted at Citizens most likely to need help soon.</p>
	<p>Block 3: Our response to Citizens who contact us for information or assistance, including information gathering, assessment and screening, the first step in a full Self Directed Support (SDS) process.</p>
	<p>Block 4: Provision of <i>immediate</i> care and support to maintain Customer safety and wellbeing until they can participate in a full SDS process; or low-level interventions made at the initial contact and screening stage.</p>
	<p>Block 5: An intensive, short-term service designed to help maximise the level of physical function (independent living capacity) of people, who wish to regain or extend their independent living skills.</p>
	<p>Block 6: Outcome focussed assessment of customer need and risk which identifies the Customer's FACS eligibility and any financial contribution that they may need to make towards their package of care.</p>



<p>Initial personal budget calculation</p>	<p>Block 7: An initial amount of social care money, indicated by a transparent resource allocation system, to fund an individual's support, some of which may be taken as a direct payment.</p>
<p>Outcome focussed support planning</p>	<p>Block 8: How Customers agree the outcomes they want their care to achieve and how they can choose, through a common and transparent framework, services to achieve their personal outcomes.</p>
<p>Authorisation and validation</p>	<p>Block 9: How the Council verifies that the funding allocation is appropriate to assessed need and that the agreed package of care will be effective in meeting the personal outcomes of the Customer.</p>
<p>Organising Support (getting services in place)</p>	<p>Block 10: How the Council or selected third party, will help Customers to identify service delivery options and to secure (broker) the support services specified in their personal support plan.</p>
<p>Service provision (live life)</p>	<p>Block 11: The period during which services have been secured and are being delivered, either by the Council, Family members, Directly employed staff or third party providers; or any combination thereof.</p>
<p>Outcome focussed monitoring and review</p>	<p>Block 12: How we will identify with Customers the extent to which their personal outcomes have been achieved and, where appropriate, agree adjustments to care plans in order to improve their effectiveness.</p>

## Appendix C



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# Prime Minister's challenge on dementia

Delivering major improvements in  
dementia care and research by 2015



**DH INFORMATION READER BOX**

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	<b>Social Care / Partnership</b>
<b>Document Purpose</b>	For Information
<b>Gateway Reference</b>	17392
<b>Title</b>	Prime Minister's Challenge on Dementia - Delivering major improvements in dementia care and research by 2015
<b>Author</b>	Older People & Dementia Team
<b>Publication Date</b>	26 March 2012
<b>Target Audience</b>	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Special HA CEs, Allied Health Professionals, GPs, Emergency Care Leads
<b>Circulation List</b>	Directors of Finance, Voluntary Organisations/NDPBs, Council of Deans of Health, Medical Royal Colleges
<b>Description</b>	This document sets out the Prime Minister's challenge on dementia, an ambitious programme of work to push further and faster to deliver major improvements in dementia care and research by 2015, building on the achievements of the existing National Dementia Strategy.
<b>Cross Ref</b>	Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy
<b>Superseded Docs</b>	N/A
<b>Action Required</b>	N/A
<b>Timing</b>	N/A
<b>Contact Details</b>	James Davison Social Care Policy - Older People & Dementia Room 8E13, Quarry House Quarry Hill, Leeds LS2 7UE 0113 2547377  <a href="http://www.dh.gov.uk/dementia">www.dh.gov.uk/dementia</a>
<b>For Recipient's Use</b>	

# PRIME MINISTER'S CHALLENGE ON DEMENTIA

*Delivering major improvements in dementia care  
and research by 2015*

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# Prime Minister's foreword

Imagine feeling confused and afraid because close friends and relatives seem like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one's face, as they struggle to make sense of familiar surroundings.

For many people in this country, this is the reality of everyday life. 670,000 people in England are living with dementia. An estimated twenty one million people in our country know a close friend or family member with dementia – that's 42% of the population. One in three people aged over 65 will have dementia by the time they die. And as life expectancy increases, more and more people will be affected.

Dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go.

Our research knowledge on dementia lags behind other major diseases such as cancer or heart disease. People with dementia and their carers still face a lack of understanding from public services, businesses and society as a whole. And as many as half of all dementia sufferers in this country are unaware that they have the condition, meaning that they cannot get the help that they and their families need.

So I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition. Of course the Government doesn't have all the answers, and we can't fix everything overnight. But with a sustained and concerted effort from all parts of society, I believe we can make a real difference – and we are determined to do so.

A handwritten signature in black ink, appearing to read "David Cameron". The signature is written in a cursive style with a long horizontal stroke at the end.



# Introduction

After a century of advances in medical science, sanitation and nutrition, people today are living longer than ever before. This is an extraordinary success story, but one that presents challenges as well as opportunities.

One in three people over the age of 65 will develop dementia. In England in 2012, 670,000 people have dementia – equivalent to the combined populations of Bristol and Leicester. This number will double in the next 30 years.

Among the over-55s, dementia is feared more than any other illness. And at an estimated £19 billion a year, the cost to our economy is huge. It is estimated that this is higher than the costs of cancer, heart disease or stroke. We have not only a moral imperative to improve dementia care – there is a strong financial one too.

*Living Well with Dementia – A National Dementia Strategy* (2009), was one of the first strategies of its kind in the world. It set the standard for improving the lives of people with dementia, for their families and their carers, through raising awareness, encouraging earlier diagnosis and providing high-quality treatment and care.

Three years on, and we've made progress (see Box 1). But we need to do more. We need to push further and faster to improve radically the quality of life for people living with dementia, their families and carers by 2015.

## Box 1: Progress on improving dementia care

- **94% of primary care trusts (PCTs) now have a dedicated memory service for dementia**, and a further 4% are planning to set up a memory service in the future, according to the first national audit of memory services published in September 2011. The average number of people using memory services per PCT increased by 57% between 2008/9 and 2010/11 (from 605 to 951).
- **The NHS and Social Care, working together with wider partners, have taken forward initiatives to reduce the prescribing of antipsychotic drugs for people with dementia to improve quality of life** with a view to achieving overall a two thirds reduction in the use of antipsychotic medicines. However, more needs to be done.
- **More than 90 leading organisations have joined the Dementia Action Alliance (DAA) since October 2010**. Organisations from health, social care, and the voluntary and commercial sectors are working together to help improve the quality of life for people with dementia, their carers and families.
- **A Dementia Commissioning Pack was launched in July 2011**, to guide NHS commissioners in getting the best possible outcomes for people with dementia and the best value for money.



## **The ambition**

We want to make a real difference to the lives of people with dementia. Building on the National Dementia Strategy, we believe that the UK can be a world leader in dementia care and research.

People with dementia, their families and carers have told us what is important to them and what will help them to live well with dementia. They say they want to receive an early diagnosis and timely, good-quality information that will help them make informed choices about their care. They want the treatment and support they receive to be the best for their dementia and life, regardless of whether they are cared for at home, in hospital or in a care home.

The Health and Social Care Bill will improve quality and choice of care for people with dementia and their carers. GPs and other clinicians who come into regular contact with people with dementia and their carers will have the primary responsibility for commissioning health and care services, which should ensure that they get the care that they need and want.

The forthcoming Care and Support White Paper will benefit people with dementia and their carers too, giving them more choice and control over their care, better information, and better-quality care.

But we will need to do more. The PM's Challenge on Dementia is a challenge to the whole of society as well as government. It will focus on three key areas:

- **Driving improvements in health and care**
- **Creating dementia friendly communities that understand how to help**
- **Better research**

As well as driving up the quality of care, work in these three areas should help to reduce future pressures on the NHS and social care.

Annex A sets out the full list of the actions being taken forward across the three areas.

# Key commitments

## Driving Improvements in health and care

- 1. Increased diagnosis rates through regular checks for over-65s.** We will ensure that GPs and other health professionals will make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- 2. Financial rewards for hospitals offering quality dementia care** From April 2012, £54m will be available through the Dementia Commissioning for Quality and Innovation (CQUIN) to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to all CQUIN rewards will be dependent on delivering support for carers in line with the National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Clinical Excellence (SCIE) guidelines.
- 3. An Innovation Challenge Prize of £1m** NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- 4. A Dementia Care and Support Compact signed by leading care home and home care providers** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.
- 5. Promoting local information on dementia services** We will promote the information offer pioneered by NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.

## Creating dementia friendly communities that understand how to help

- 6. Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.
- 7. Support from leading businesses for the PM's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia friendly society and raising awareness of dementia.
- 8. Awareness-raising campaign** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.
- 9. A major event over the summer, bringing together UK leaders from industry, academia and the public sector,** to take forward the PM's Challenge on Dementia.

## Better research

- 10. More than doubling overall funding for dementia research to over £66m by 2015**  
The combined value of the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) funding

for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.

- 11. Major investment in brain scanning.** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants.
- 12. £13m funding for social science research on dementia (NIHR/ESRC).**
- 13. £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia-themed research will share their considerable resources and world-leading expertise to improve treatment and care.**
- 14. Participation in high-quality research** Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services.

# Driving improvements in health and care

The implementation of the National Dementia Strategy is beginning to improve the lives of people with dementia, but we need to do more to improve the quality of care. Failure to act will mean our health and social care services will struggle under the pressure of increasing numbers of people with dementia. **We must ensure that every person gets the treatment and support which meets their needs and their life.**

The NHS reforms will improve quality and choice of care for people with dementia and their carers. GPs and other clinicians who come into regular contact with people with dementia and their carers will have the primary responsibility for commissioning health care, which should ensure that they get the care that they need and want. The forthcoming Care and Support White Paper will set out a range of proposals that will benefit people with dementia and their carers, giving them more choice and control over their care, better information, and a greater assurance of quality. Our reforms will enable a much more integrated approach with health and social care services centred around people's needs.

## **Better diagnosis**

Currently only 42% of people with dementia in England have a formal diagnosis. The diagnosis rate varies – from 27% in the worst-performing areas to 59% in the best. Too often, diagnosis comes too late – during a crisis or beyond the point where people can plan for the future and make informed choices about how they would like to be cared for. This is not good enough.

Surveys show us that people with dementia would like early diagnosis. And we know that with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

The people most at risk of developing dementia (the over-75s) see their GP at least once, if not several times, a year. Around 97% of people aged over 75 go to their GP surgery at least once a year, and around 87% at least once every six months.

### Key commitment 1

***Increased diagnosis rates through regular checks for over-65s*** We will ensure GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.

Clinical commissioning groups and local health and wellbeing boards will be encouraged to work with wider local partners to improve diagnosis rates. We will incentivise improved diagnosis rates by including a new indicator in the NHS Outcomes Framework 2013/14.

## Improving care in hospitals

A quarter of all hospital beds are occupied by someone with dementia, and many hospitals struggle to provide the high-quality care that meets the needs of people with dementia. But others get it right. There are examples of excellent and innovative practice across care settings. We need to support this good practice and encourage it to develop and spread.

### Key commitment 2

***Financial rewards for hospitals offering quality dementia care*** From April 2012, £54m will be available through the Dementia CQUIN to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to CQUIN rewards will be dependent on delivering support for carers in line with NICE/SCIE guidelines.

### Key commitment 3

***An Innovation Challenge Prize of £1m*** NHS staff can win up to £1m for innovative ideas for transforming dementia care.

## Improving standards in care homes and domiciliary care

While many care homes and care-at-home services offer excellent support for people with dementia, some are not doing enough. We need to make sure that whether people are being cared for in their own home, or in care homes, the staff who work with them have the knowledge and skills to help them lead as fulfilling a life as possible.

### Key commitment 4

***A Dementia Care and Support Compact signed by leading care home and home care providers.*** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.

## Better information for people with dementia and their carers

People with dementia and their families and friends would like better information about health and care services. They want to know what they are entitled to, so that they can be sure they are getting all the support they need. Greater transparency in health and care services can also drive up quality and empower people with dementia and their carers.

But currently, the quality of advice and information which people receive is variable. In all too many areas, it is extremely difficult for people with dementia to find out what support is available and to what they are entitled to.

In 2011/12, primary care trusts were asked to work with their local authorities to publish dementia plans which set out the progress they were making locally towards implementing the National Dementia Strategy. We will do preparatory work that will mean that clinical commissioning groups, working with health and wellbeing boards, are able to go further and provide a transparent local information offer to support people with dementia and, crucially, their carers.

#### Key commitment 5

***Promoting local information on dementia services*** We will promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.

In the South West, the local NHS, local authorities and the Alzheimer's Society have produced a web-based information service called Our Health. This uses the NICE quality standards and other evidence to provide information on the support people with dementia should expect to receive. Our Health describes the different services available across the South West, how they can be accessed, and the quality of care they are likely to receive. People also have the opportunity to give feedback on their experience.

#### **Better support for carers**

There are around 550,000 people in England acting as the primary carers for people with dementia. Carers for people with dementia save the nation nearly £7 billion every year. Research shows that carers of people with dementia experience greater strain and distress than carers of other older people.

We want to see better support for carers. The NHS is now required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources and make sure that carers get the support and break they deserve. We have provided an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role. The NHS should also ensure that a range of psychological therapies and support is available to carers of people with dementia in line with NICE/SCIE dementia guidelines.

The NHS and Social Care working together with wider partners should continue to reduce inappropriate prescribing for people with dementia to improve quality of life with a view to achieving overall a two-thirds reduction in the use of antipsychotic medication.

#### **CHAIR OF THE CHAMPION GROUP**

Co-chair: Sir Ian Carruthers

Co-chair: Sarah Pickup

### **Case study: A personal experience of early diagnosis**

**I was diagnosed with dementia six years ago at the age of 50. Although I struggled for three years to get my diagnosis because of my young age, I was still able to receive my diagnosis while in the early stages. I first noticed symptoms 10 years ago when I started to struggle in my job as a teacher – I was forgetting things and struggling to organise classes. I also lost my mathematical ability. I was put on Aricept straight after my diagnosis, which made a huge positive difference to my quality of life. Life doesn't have to end after receiving a diagnosis; you just have to start making choices. I have a very positive outlook and think it is extremely beneficial to have an early diagnosis as it enables you to make important choices and decisions that can help you live life well. I still enjoy playing tennis and regularly go on holiday.**

***Person with dementia***

# Creating dementia-friendly communities that understand how to help

The health and care system has a vital role to play in improving support for people with dementia. But alone it cannot combat the stigma attached to dementia. Lack of awareness among the public and poor understanding in communities has a major impact on the experience of people with dementia. This is a call to action across the whole of society. **We would like people living with dementia to be able to say that they know what they can do to help themselves and who else can help them, and that their community is working to help them to live well with dementia.**

## **Dementia-friendly communities**

People living with dementia want to remain independent for as long as possible, and they want to have choice and control over their lives through all stages of their dementia. With an early diagnosis and the right support they can achieve this.

But this is not the experience of the vast majority of people living with dementia. Not only do they frequently have to battle for diagnosis and support, but everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday – are made difficult because of the limited understanding of dementia in their communities.

People with dementia talk about stigma and social isolation. They report losing friends following their diagnosis, seeing people cross the street to avoid them, feeling lonely, and struggling to use local services. Research with the general public has shown that this is often down to the fear, misunderstanding and helplessness people feel in the face of dementia. They simply do not understand enough to support someone to live well with dementia.

The common misunderstandings about dementia – that it's an inevitable part of ageing and that nothing can be done to improve people's lives – prevents our communities and society from becoming more dementia-friendly and meeting the needs of people with dementia and their families. As a society, we must make sure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition.

Building more dementia-friendly communities will take time. The Alzheimer's Society will take the lead, working with members of the Dementia Action Alliance to create a formal dementia-friendly recognition process that will make villages, towns and cities accountable to people with dementia and their carers through local Dementia Action Alliances. They will identify what villages, towns and cities need to do to be recognised as dementia-friendly. Only villages, towns and cities that meet their criteria will be granted dementia-friendly community status.



Key commitment 6

***Dementia-friendly communities across the country*** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.

Key commitment 7

***Support from leading businesses for the PM's Challenge on Dementia.*** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.

**Public understanding**

Despite the rising numbers of people living with dementia, public understanding of the condition is limited and populated with misconceptions. Poor understanding of dementia has a fundamental impact on the health and well-being of people with dementia. It can lead to their rights not being recognised and families and the economy being put under serious strain. People with dementia, their carers and families struggle to remain independent in a society that does not understand dementia or how to support those affected by dementia to live well with it.

Key commitment 8

***Awareness-raising campaign*** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.

Key commitment 9

***A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.***

**CHAIR OF THE CHAMPION GROUP**

Co-chair: Angela Rippon

Co-chair: Jeremy Hughes

### **Case study: A dementia-friendly city – York**

**In York, the Joseph Rowntree Foundation is funding a year-long project exploring how local partners, including people who are living with dementia and their families, can make the city of York a better place for those affected by the condition. The Dementia Without Walls project will use the experiences of people with dementia, and those who support and care for them, to consider how life can be lived to the full. Also, drawing on examples of current best practice locally, nationally and internationally, the project will challenge people to think afresh, not only about health and social care services, but housing, shopping, leisure and transport. In other words, the everyday amenities that most people take for granted, but which can create enormous challenges for people with dementia. A core aim will be creating opportunities for people with dementia to experience different kinds of services. This will be done through ‘seeing is believing’ visits (to see different places and services where innovative approaches are being tried) and by sharing their experiences with other service users.**

# Better research

While the UK is considered one of the top five countries for dementia research, there are still major challenges, including significantly increasing dementia research capacity and capability; understanding better the mechanisms of the disease and likely targets for intervention; and translating research into practice that affects quality of life. **We would like people to feel confident that we are making significant progress towards prevention, treatment and cure in the UK, and to be able to say that they wanted to take part in research and were able to do so.**

## Funding more high-quality research into care, cause and cure

Delivering on the commitment to enable people with dementia and their carers to participate in research will involve work to raise the volume of high-quality studies in the system – across the fields of care, cause and cure.

While it is important to ensure that all areas of scientific work are covered, consultation with experts in the field indicates that some of the greatest opportunities for further scientific progress – for finding the causes and cures for this devastating condition – lie at the early stage 'discovery' end of the scientific spectrum. There are also opportunities for social science research focused on living well with dementia and on the delivery of dementia care services.

### Key commitment 10

***More than doubling overall funding for dementia research to over £66m by 2015. The combined value of the NIHR, MRC and ESRC funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.***

### Key commitment 11

***Major investment in brain scanning*** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants.

Note: The UK Biobank is the largest study in the world to determine the environmental and genetic factors that influence how we age, including the risks of developing dementia. This long-term programme has already recruited 500,000 people between the ages of 40 and 69.

### Key commitment 12

***£13m funding for social science research on dementia (NIHR/ESRC)***

### Key commitment 13

***£36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which***

***include dementia-themed research will share their considerable resources and world leading expertise to improve treatment and care.***

## **Participation in research**

Compared with other conditions such as cancer, the level of public engagement in research, by donation or by direct participation in studies, is low. When people are offered the opportunity to take part in the research, they are often keen to do so. However, people with dementia and their carers are not routinely offered the opportunity to participate in high-quality research and there is no nationally consistent system to enable them to do so, should they wish.

### Key commitment 14

***Participation in high-quality research*** *Offering people the opportunity to participate in research will be one of the conditions of accreditation for memory services.*

## **CHAIR OF THE CHAMPION GROUP**

This work will continue to be led by the Ministerial Advisory Group on Dementia Research (MAGDR) on behalf of Paul Burstow MP, Minister of State for Care Services. The group itself will be co-chaired by Dame Sally C Davies and Sir Mark Walport.

## **Case study: Living Well with Dementia research**

**Topic: Living Well with Dementia: the contribution of dementia advisers and peer support networks**

**Funded by: DH Policy Research Programme: £650,000**

**Research team: School of Health in Social Science, University of Edinburgh**

### **Background**

The National Dementia Strategy (NDS) stresses the importance of promoting the quality of life and well-being of those living with dementia and their carers. As part of the implementation of the NDS, dementia advisers and peer support networks were established in 40 demonstrator sites across England. These have developed a range of different methods and approaches for enhancing the well-being and increasing the resilience of those living with the disease. Evaluation was built into the developments of the new service models from the beginning, both at a local level and nationally.

### **The study**

The study's aims are threefold:

- to describe the range of dementia adviser and peer support organisational models developed; and their evolution, management and governance;
- to evaluate the impact of the new service models in terms of:
  - the well-being of patients and carers;
  - their contribution to the objectives of the NDS;
  - the integration, sustainability and transferability of the organisational models involved.
- to examine in depth the patient/carer experience of the new service models, in respect of increasing accessibility, improving involvement and information, enhancing support for making choices, and increasing independence.

### **Progress**

The study began on 1 April 2010 and is due to complete in September 2012. Interim findings indicate:

- strengthened partnership working;
- increased awareness of dementia on the part of providers;
- support provided being seen to fill a 'gap' in existing provision;
- a perceived reduction in carer stress;
- appreciation from other providers of the value of the new services;
- a reduction in demand for statutory services; and
- a network built on the commonality of experience.

# Next steps

The commitments set out in the Prime Minister's Challenge on Dementia will be taken forward by a range of partners across health and social care, the research and industry sector, and broader society. Three **champion groups** will bring together leading organisations and groups with an interest, to support the delivery of the commitments and to mobilise wider engagement. The champion groups will report on progress to the Prime Minister through Department of Health (DH) ministers. Each will comprise co-chairs and 10–15 members drawn from key sectors, including health and social care, industry and the third sector.

## **Champion groups**

### ***Driving improvements in health and care***

Co-chairs: Sir Ian Carruthers (NHS South West) and Sarah Pickup (ADASS)

### ***Creating dementia-friendly communities that understand how to help***

Co-chairs: Jeremy Hughes (Alzheimer's Society) and Angela Rippon

### ***Better research***

Led by the existing Ministerial Advisory Group on Dementia Research (MAGDR), with the work co-chaired by Dame Sally C Davies and Sir Mark Walport (Wellcome Trust)

## **Measuring progress**

Progress will be reported to the Prime Minister in September 2012. Thereafter progress will be reported to the Prime Minister in March 2013 and the Department of Health will review future reporting arrangements.

# Conclusion

Dementia is undoubtedly one of the major health and social care issues of our time. Until recently it was also one of the most ignored. The National Dementia Strategy has made a good start in addressing the needs of people with dementia, but we need to make more rapid progress. The wide range of new measures in this document demonstrate the Government's commitment on tackling dementia. By 2015, we intend that every person with dementia will be able to say the following:

"I get the treatment and support which are best for my dementia and my life."

"I know what I can do to help myself and who else can help me. My community is working to help me to live well with dementia."

"I wanted to take part in research and was able to do so."

Through research, we will in time find a cure. But until we do, every effort must and will be made to improve the lives of people with dementia and their families and carers.

# Annex A: List of actions

## Driving improvements in health and care

- **Increased diagnosis rates through existing checks for over-65s** We will ensure that GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- **Financial rewards for hospitals offering quality dementia care** From April 2012, £54m will be available through the Dementia CQUIN payment framework to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also, for April 2013 access to all CQUIN rewards will be dependent on delivering support for carers in line with the NICE/SCIE guidelines.
- **An Innovation Challenge Prize of £1m** NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- **A Dementia Care and Support Compact signed by leading care home and home care providers** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage, involve the wider community in this work.
- **We will promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012** From April 2013, information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure all people receiving care and support get better information to support their care choices.
- **We will work with the profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the GP contract.**
- **We will ask NICE to consider ways of improving the dementia indicators in the Quality and Outcomes Framework.**
- **We will call on the Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care.** The Royal Colleges have committed to driving this forward.
- **We will ensure that memory clinics are established in all parts of the country, and will work with the Royal College of Psychiatrists to drive up the proportion of memory services that are accredited, through publication of their national Memory Services Accreditation Programme, so that individual organisations can benchmark and report their own performance to drive improvement.**



- **The NHS will guarantee a written integrated personalised care plan to people with dementia.**
- **There will be better support for carers** The NHS is required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources, and make sure that carers get the support and break they deserve and that young carers do not take on excessive or inappropriate caring roles. We have made available an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role.
- **Carers have the right to be assessed and their needs met** In addition we know carers can take their support as a personal budget and they are encouraged to do so. The NHS should also ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines, as well as ensuring services are made available to support the couple relationship where one person is caring for a partner with dementia.
- **By September 2012 we will launch pilots of dementia clinical networks aimed at spreading clinical expertise.**
- **We welcome the Nursing and Care Quality Forum's forthcoming views on what should be done to address the needs of people with dementia as part of its work to spread best practice in nursing and care in all care settings.**

### **Creating dementia friendly communities that understand how to help**

- **Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.
- **Support from leading businesses for the PM's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.
- **Awareness-raising campaign** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous pilot campaigns and will inform future investment.
- **A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.**
- **We will work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations, funded by £537,000 from the Department of Health over three years.**
- **We will make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society.**

- **The Dementia-friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a dementia-friendly community is.**

## **Better research**

- **More than doubling overall funding for dementia research to over £66m by 2015.** The combined value of the NIHR, MRC and ESRC funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.
- **Major investment in brain scanning** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50–100,000 participants.
- **£13m funding for social science research on dementia (NIHR/ESRC)** including £3m for public health research.
- **£36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia themed research will share their considerable resources and world leading expertise to improve treatment and care.**
- **Participation in high-quality research** Consent to participate in research will be one of the conditions of accreditation for memory services.
- **The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients** This includes £500k a year to improve the process for donation of brain tissue by meeting the costs of collecting brain tissue through the NHS, so smoothing the pathway to donation.
- **A major event will be staged for pharmaceutical and biotech companies to showcase the benefits of conducting dementia research in the UK, and to assess how best to remove the barriers to doing so.**
- **We will work towards recruiting 10% of patients into clinical trials.**
- **Up to £9m of DH funding will be made available for research into ‘living well with dementia’ and the delivery of dementia care.**
- **The DH will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.**
- **The MRC is a leading partner in two international initiatives in the area of neurodegeneration research: the European ‘Joint Programming’ initiative which aims to coordinate national efforts in this area; and the Centres of Excellence Network in Neurodegeneration (CoEN) which seeks to add value to existing investments in excellence.**

- **The world-leading MRC Laboratory of Molecular Biology (LMB) is moving to its new £200m facilities in Cambridge in the autumn** Within this, the Neuroscience Research Division has been provided with an expanded budget of £29m over the next three years, with a major part of its research dedicated to dementia/neurodegeneration.
- **The NIHR has also just completed a first-ever themed call for proposals in dementia research** Some £17m will be committed to new research projects through this call, exceeding original expectations. The 18 projects to be funded range from work on better diagnosis to improving care in a wide range of settings, from individual's own homes, through residential care to specialist hospitals.

# Annex B: Dementia Care and Support Compact

## Introduction

This Dementia Care and Support Compact is our response to the Prime Minister's Challenge on Dementia. It sets out our commitment to supporting the delivery of the National Dementia Strategy and improving care and support for people with dementia, their carers and families.

## Our challenge

We challenge the perceptions surrounding social care services for people with dementia. Our services will provide the right care, in the right place, at the right time.

People with dementia using our services will be able to say:

- I am respected as an individual.
- I get the care and support which enables me to live well with my dementia.
- Those around me and looking after me are well supported and understand how to maximise my independence.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me.
- I can enjoy life.
- I feel part of a community and I am inspired to participate in community life.
- I am confident that my end-of-life wishes will be respected. I can expect a good death.

## Our commitment

We will:

- focus on quality of life for people with dementia, as well as quality of care. By knowing the person, their life history and their personal culture, our staff will deliver a personalised package of care and support;
- set a benchmark for high-quality relationship-based care and support for people with dementia. We will inspire and encourage our sector to take responsibility for delivering this, building on existing good practice;
- engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals;
- play our part in supporting the wider community, sharing the knowledge and skills of our staff, and inviting people into our care settings;
- work with commissioners of care for people with dementia to ensure they commission quality care services appropriately; and
- clearly set out how we have delivered on this Compact to make a difference for people with dementia, their carers and families. This will link into the work on quality and transparency being taken forward as part of the Care and Support White Paper.

## **Signatories**

Martin Green, Chief Executive, English Community Care Association and DH Independent Sector Dementia Champion

Jane Ashcroft, Chief Executive, Anchor

Mike Parsons, Chief Executive, Barchester Healthcare

Stuart Fletcher, Chief Executive, BUPA

Mike Parish, Chief Executive, Care UK

Miranda Wixon, Executive Committee Member, CERETAS

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2900094 28p 1k March 2012  
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