

# 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 speak 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 practices 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 practice 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 affects. 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/respice 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?***

As a result of the co-production approach adopted in order to produce this joint dementia strategy, there are a wide range of actions that need to be incorporated into the resulting Action Plan – see Appendix One.

This 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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**Joint Dementia Strategy Action Plan**

<b>What do we want to achieve?</b>	<b>Quality Standard</b>	<b>What will we do to achieve this?</b>	<b>How much will it cost?</b>	<b>When will it be achieved by?</b>	<b>Who is taking the lead?</b>
Good Quality Early Diagnosis Improved public and Professional Awareness	'I was diagnosed early' "I was treated with dignity and respect"	To develop and deliver a rolling programme of public awareness events over the next two years about recognising and understanding dementia	£0.050M per annum (NHS Support for Social Care) This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	March 2013	Wolverhampton Council
Good Quality Information for People with Dementia and Carers	'I understand, so I make good decisions and provide for future decision making'	Develop a support service through the creation of two dementia advisor posts, one post with skills in Asian languages. Service to be based within the Brokerage Service. Fixed term contract. This will be formally evaluated.	£0.050M per annum, including on-costs from the Commissioning Development Fund	April 2013	Wolverhampton Council
An Informed & Effective Workforce	"I get the treatment and support which are best for my dementia and my life"  "I am confident that my end of life wishes will be respected"	University of Worcester has been commissioned to deliver further Dementia Leadership and Champion Modules to Commissioned Providers Across the City  Commission Bradford Dementia Group to complete baseline mapping to 10% Care Homes & produce improved action plan & review. This work links with The University of Worcester Training which will be formally evaluated	£0.035M per annum from Learning and Development Funds and NHS Support for Social care. This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	September 2012	Wolverhampton Council

	“I can expect a good death”	<p>A dementia awareness programme for staff providing long-term care of people with dementia including GPs. Training of Mental Health Staff in common physical illnesses</p> <p>Continued roll out of education programme for all staff in the area, led by Royal Wolverhampton Hospital Trust</p>	<p>£40,000 (NHS support for reablement and integrated working)</p> <p>Dementia education budgets (RWHT)</p>	<p>March 2013</p> <p>March 2013</p>	<p>Wolverhampton City PCT</p> <p>Royal Wolverhampton Hospital Trust</p>
Good Quality Early Diagnosis	“I was diagnosed early”	Commission a Primary Care Liaison Worker to work with clients, GP practices and mental health services to improve early diagnosis	£90,000 (NHS support for reablement and integrated working)	March 2013	Wolverhampton City PCT
Improved Community Personal Support	“I get the treatment and support which are best for my dementia and my life” “I can expect a good death”	Commission Dementia Pathway. Co-ordination and pathway workers to improve integrated care. Pathway workers will offer a continuing low level intensity support for people with dementia	£327,000 (NHS support for reablement and integrated working)	April 2013	Wolverhampton City PCT
Structured Peer Support and Learning Networks Carers Strategy Improved	“I can enjoy life; I feel part of a community and I’m inspired to give something back”	Commission Alzheimer’s Society to deliver three additional Dementia Cafés – One for African Caribbean Elders; One for people with early onset dementia	£0.037M per annum through Commissioning Development Fund	September 2012	Wolverhampton Council

Community Personal Support High Quality Service in Care Homes Informed and effective Workforce	"I get the treatment and support which are best for my dementia and my life"	Development of Workforce Strategy for Adults, including a priority for dementia services. This strategy will adopt the 4 objectives quoted in the Workforce Strategy.	Through in-house resources	April 2012	Wolverhampton Council
Improved Public and Professional Awareness	"I was diagnosed early" "I am treated with dignity and respect"	Delivery of awareness briefings to third sector organisations and universal services Delivery of awareness briefings to community Members Delivery of awareness briefings for health staff	Through in-house resources – Learning and Development Funding Through in-house resources within partner organisations	September 2012 September 2012	Wolverhampton Council Wolverhampton City PCT
Improved Community Personal Support Good Quality Early Diagnosis and Intervention	"I get the treatment and support which are best for my dementia and my life"	Development of health and social care domiciliary short term input re-enablement service for people with dementia. An integrated reablement pathway for people with dementia will be produce which will include younger adults. The focus will be on early intervention, community services and hospital discharge. Increase in occupational therapy support to rehabilitation wards at West	Efficiency savings will be released through the development of a high quality evidence-based business plan £105,000 (NHS support for	April 2012 This will be accomplished with the University of Birmingham through the Integrated Development Programme March 2013	Wolverhampton Council Wolverhampton City PCT

	Park Hospital	reablement and integrated working)			
Improved Community Personal Support	<p>"I get the treatment and support which are best for my dementia and my life"</p> <p>"I can expect a good death"</p>	Commission additional community matron and occupational therapy expertise to work closely with mental health teams. Aim: more people with dementia and a physical health problem to be cared for in the community	£145,000 (NHS support for reablement and integrated working)	September 2013	Wolverhampton City PCT
Good Quality Care in Hospital	<p>I get the treatment and support which are best for my dementia and my life"</p>	Evaluate the pilot work at Royal Wolverhampton Hospital Trust (RWHT). Commission services as indicated from the outcomes of this national research work. Continue structured education programme in RWHT as above	In-house commissioning team	April 2012	Wolverhampton City PCT
Housing & Telecare	<p>"I know what I can do to help myself and who else can help me"</p>	Development and delivery of telehealthcare in Care Homes	Within current resources	June 2012	Wolverhampton City PCT
Housing & Telecare	<p>"I get the treatment and support which are best for my dementia and my life"</p>	Development and delivery of telehealthcare in Very Sheltered Housing Schemes	£0.100M per annum for next two years (NHS Support for Social Care). This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	October 2012	Wolverhampton Council
Housing & Telecare	<p>"I get the treatment and support which are best for my"</p>	To upgrade existing equipment in Sheltered Housing Schemes	£0.183M per annum for next two years (NHS Support for Social Care). This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	October 2012	Wolverhampton Council
Housing & Telecare	<p>"I get the treatment and support which are best for my"</p>	To upgrade existing equipment in Sheltered Housing Schemes	£0.020M NHS Support for Social Care). This DH funding is	December 2012	Wolverhampton Council

	dementia and my life"			available until end of March 2013. Sustainable plan or exit strategy needed		
Housing & Telecare	"Those around me & looking after me are well supported	To commission a registered domiciliary care agency to provide an emergency response	£0.070M (NHS Support for Social Care). This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	January 2012	Wolverhampton Council	
Easy Access to Care and Support	"I can enjoy life, I feel part of the community & inspired to give something back"	Third Sector Innovation Funding 'Think Local Act Personal'	(NHS Support for Social Care £0.500M per annum This DH funding is available until end of March 2013. Sustainable plan or exit strategy needed	March 2012	Wolverhampton Council	
Intermediate Care	"I get treatment & support which are best for my dementia & my life"	Reconfigure existing services in the Resource Centres to Intermediate care beds that are appropriate for people with dementia & develop service level agreements with the in-house provider  Introduce improved IT solutions to ensure good timely integrated communications between hospital, community and social care	Use mainstream funding  £157,000 (NHS support for reablement and integrated working)	December 2013  April 2013	Wolverhampton Council  Wolverhampton City PCT	
Carers Strategy	"Those around me & looking after me are well supported"	To ensure service specifications for Day Services incorporate the needs of people with dementia	Within existing resources	September 2013  July 2012	Wolverhampton City PCT  Wolverhampton Council	

Carers Strategy	“Those around me & looking after me are well supported”	To develop a dedicated Day Services for Asian Elders at Blakenhall Resource Centre & develop service level agreement with in-house provider	Within existing resources – No extra cost	April 2012	Wolverhampton Council
Carers Strategy	“Those around me & looking after me are well supported”	To promote Blakenhall Day Resource as a citywide service.	Within existing resources – No extra cost	January 2012	Wolverhampton Council
Improved Community Personal Support	“I know what I can do to help myself & who else can help me”	Improve domiciliary service specification and monitoring	Commissioning time & expertise	April 2012	Wolverhampton Council
High Quality Services in Care Homes	“I get the treatment & support which are best for my dementia and life”	Improve care home service specification and monitoring	Commissioning time & expertise	April 2012	Wolverhampton Council
An Informed and Effective Workforce	“I get the treatment & support which are best for my dementia and life”	To complete a skills audit	Within existing Resources	January 2012	Wolverhampton Council
High Quality Services in Care Homes	“I get the treatment & support which are best for my dementia and life”	Introduction of register in care homes for anti-psychotic medicines	No extra cost – within existing contract	April 2012	Wolverhampton Council
Improved Community Personal Support	“I get the treatment & support which are best for my dementia and life” “I can expect a good death”	Provision of additional equipment to support people to live at home, to reduce unnecessary admission to hospital and earlier discharge, including at the end of life.	£200,000 (NHS support for reablement and integrated working)	April 2013	Wolverhampton City PCT
Improved Community Personal Support & Good Quality Care in Hospitals	“I get the treatment & support which are best for my dementia and life”	Improve health service specifications and monitoring	Within existing resources – No extra cost	April 2012	Wolverhampton City PCT

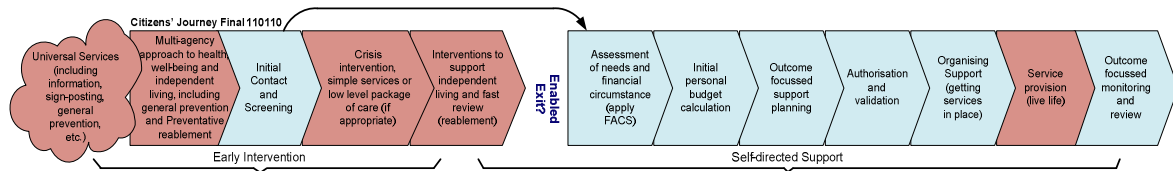
Improved Community Personal Support & Good Quality Care in Hospitals	"I get the treatment & support which are best for my dementia and life"	Continue to complete regular audits regarding antipsychotics use for people with dementia. Target education and improvements based on information obtained.	Within existing resources – No extra cost	September 2012	Wolverhampton City PCT
Improved Community Personal Support & Good Quality Care in Hospitals	"I get the treatment & support which are best for my dementia and life"	Implement local guidelines for the safe use and discontinuation of antipsychotics medication for GPs	Within existing resources – No extra cost	April 2012	Wolverhampton City PCT
Carers' strategy & Improved Community Personal Support	"I get the treatment & support which are best for my dementia and life" "Those around me & looking after me are well supported"	Improve access to the current education programme for carers regarding management of the behavioural symptoms of dementia	Within existing resources – No extra cost	September 2012	Wolverhampton City PCT
Improved Community Personal Support	"I get the treatment & support which are best for my dementia and life"	Promote the access for people with dementia and carers to Healthy Minds services	Within existing resources – No extra cost	September 2012	Wolverhampton City PCT
Better Regulation and Assessment	"I get the treatment & support which are best for my dementia and life"	Commission project support to monitor and manage the new initiatives. Ensure that all investments in services are delivering good quality outcomes for patients and carers and that they are cost-effective	£80,000 (NHS support for reablement and integrated working)	April 2013	Wolverhampton City PCT
Good end of Life Care	"I am confident that the end of my life wishes will be respected" "I can expect a good death"	Continue to roll out education and awareness for all staff across the area regarding end of life care and advanced planning.	Within existing resources – No extra cost	September 2012	Wolverhampton City PCT

## Appendix Two

### 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>Universal Services (including information, sign-posting, general prevention, etc.)</p>	<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>Multi-agency approach to health, well-being and independent living, including general prevention and Preventative reablement</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>Initial Contact and Screening</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>Crisis intervention, simple services or low level package of care (if appropriate)</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>Short-term interventions and reviews to Improve independent living outcomes (reablement)</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>Assessment of needs and financial circumstance (apply FACS)</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>