

Living Well with Dementia

A Dementia Strategy for Dudley

2013-2015

Developed in partnership with:

- **Dudley Clinical Commissioning Group**
- **Dudley MBC**
- **Dudley and Walsall Mental Health Partnership Trust**

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(Please note where relevant the strategy will include local stories/experiences to capture real issues and scenarios)

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1. INTRODUCTION

This draft strategy has been prepared jointly by a multi-agency group consisting of Dudley Clinical Commissioning Group, Dudley MBC, Dudley Walsall Mental Health Partnership Trust and representatives of the Voluntary Sector including Dudley Alzheimer's Society and Age UK Dudley.

The Dudley Strategy for Dementia 2012-2015 is based on national guidance, set out in *Living well with dementia: A National Dementia Strategy*, 2009 **1**(NDS), the subsequent Department of Health *Quality Outcomes for people with Dementia* **2**, the NICE Quality Standard for Dementia **3** and the report from the West Midlands Quality Review Services 'Review of Dementia Services for the Dudley Health Economy'.

The purpose of the Strategy is to provide an overarching statement of how the objectives of the National Dementia Strategy and other evidence based guidance can be collectively met and form an integrated care pathway. The strategy is committed to the quality standard that dementia services should be commissioned from and coordinated across all agencies to deliver high quality care for people with dementia via an integrated approach **4** (see current pathway below).

The Strategy aims to refocus investment and current resources to improve access to high quality diagnosis, treatment, support, and advice for all people living with dementia in order to improve quality of life from diagnosis to end of life for people with dementia and their carers. This includes ensuring that people with dementia and their carers receive health care and social support from staff who have the skills and training to provide the best quality care and support.

It also aims to support people (and their carers) to be cared for in their preferred place of care and reduce the number of people prematurely entering long term care.

The Strategy is underpinned by the commitment to the values of dignity and respect and the principles of Personalisation and person centred support, to enable individuals to make choices regarding their care needs; thereby maximising opportunities for independence and improved quality of life.

The Strategy is designed to be inclusive of all citizens in Dudley including those of working age. It is also inclusive of all user groups including for example, adults who may have a learning disability or other long term health conditions that impact on their cognitive abilities.

¹http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

² Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy*, Department of Health, September 2010

³ <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/>

⁴ NICE Quality Standard for dementia 2010

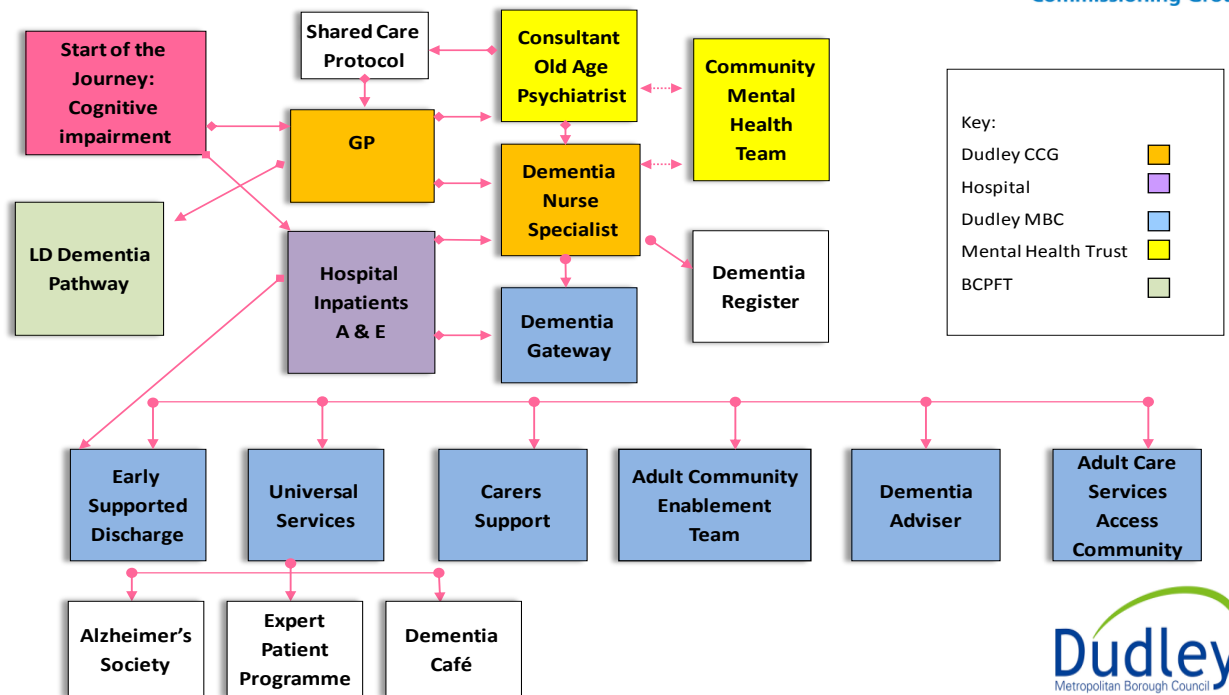
The Strategy is based on national and local evidence (where available), drawing together published data on cost-effective commissioning and care provision, and estimates on current and future costs. The Department of Health (DH) is in the

process of commissioning a baseline audit of dementia which will include data on costs.

WHAT DOES THE DUDLEY INTEGRATED DEMENTIA PATHWAY LOOK LIKE?



Dudley Clinical Commissioning Group



There are also functional and organic pathways which are in development which will be incorporated in the final strategy.

We aim to improve services by:

- Developing and re-designing clear pathways for people to access and move through services
- Improving the patient experience and quality of life
- Strengthening joint working across agencies, developing new models of service provision
- Standardising one holistic assessment process across all agencies
- Improving the service in line with evidence based research and meet or exceed the recommendations in relevant policies or guidelines.
- Monitoring & evaluating the impact of these changes by consulting with service users and carers on the impact of these changes on the service provided.
- Challenging ageist stereotypes

2. VISION

Our Vision

NHS and Social Care services in Dudley seek to commission a high quality, integrated and evidence based dementia service for people which is appropriate to need – delivering the Right Service, in the Right Place for the Right Need in a timely, responsive and non discriminatory manner

We aim to develop dementia services that are person centered and promote independence, well-being and choice.

We will aim to raise awareness of dementia and the services provided across Dudley. This will include reaching out to the isolated, BME community and those with sensory and physical disabilities.

We seek to develop integrated services between health and social care and engage fully with colleagues in the Independent and Voluntary and Community Sectors in achieving a co-ordinated and effective service.

Services should support people, as appropriate, in the community and preferably in their own homes as far as possible but with specialist support and in-patient or care home placement when necessary.

We recognise the importance of securing quick and accurate diagnoses at the earliest possible time and that means strengthening the skills and capacity within primary care.

We are committed to equality of opportunity and strive to address health inequalities across the diverse population of Dudley borough

People with dementia and their carers should have access to the same range of services as Working Age Adults including access to counselling and therapeutic services.

We are committed to the development of integrated pathways of care to provide people with co-ordinated and consistent care.

3. Background and context of dementia

What is dementia?

Dementia is regarded as a severe and devastating disorder which impacts not only on the individuals with dementia but also on the family members who care for them. It is not a disease in itself but the term used for a collection of symptoms including changes in memory, reasoning and communication skills with a gradual loss of ability to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain such as those which occur in Alzheimer's disease. The main symptoms of dementia are progressive memory loss, disorientation and confusion.

Vascular dementia – associated with diabetes, hypertension and arteriosclerosis. Good control of these other illnesses is important. It is caused by problems with the supply of oxygen to the brain.

Alzheimer's disease –this is the commonest with an insidious onset and slow deterioration. It is now more important to identify this as drug treatments are beginning to become available. Alzheimer's disease changes the chemistry and structure of the brain, causing brain cells to die.

Lewy Bodies – is caused by protein deposits that develop inside nerve cells in the brain and interrupt its normal functioning.

Fronto-temporal – is a rare form of dementia encompassing Pick's disease and it often affects the under 65's.

Who is affected?

Dementia is one of the main causes of disability. It affects adults of all ages and includes people with learning disabilities. In the UK there are 700,000 people with dementia now. In 30 years this number will double to 1.4 million.

The annual overall economic cost is £17 billion. The economic contribution of unpaid carers is £7 billion.

4. HOW MANY PEOPLE IN DUDLEY HAVE DEMENTIA?

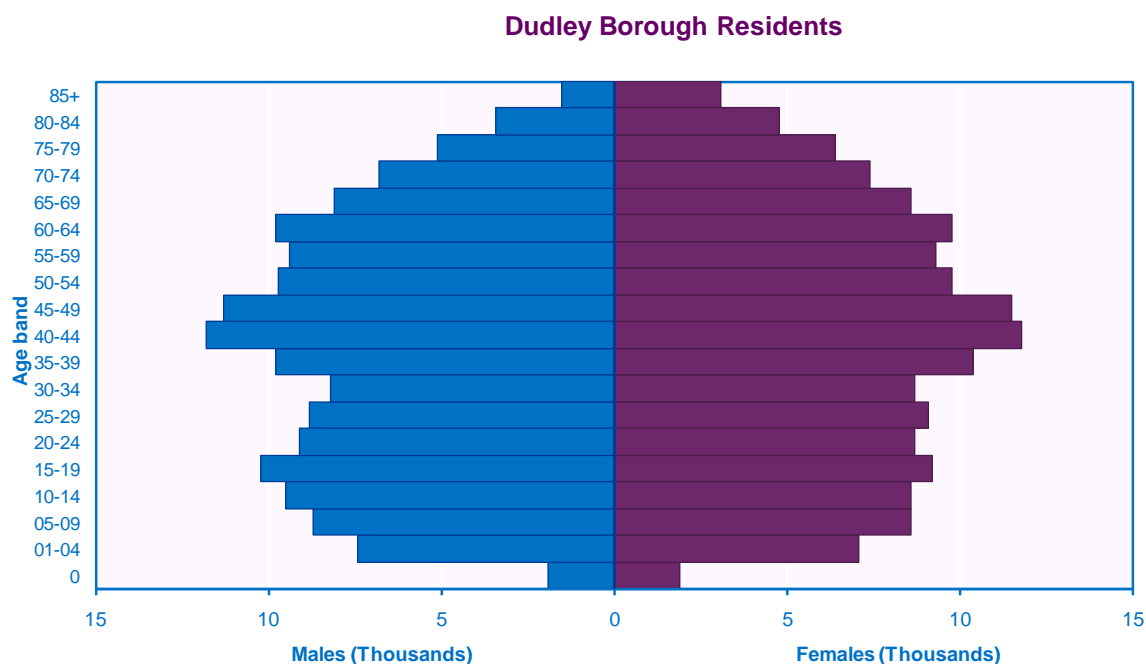
The Dudley Population

In Dudley in 2010, 57,400 people out of a total population of 307,500 are estimated to be over 65 (18.7%).

Although the population of Dudley is forecast to increase by just 2% by 2020; the number of people aged over 75 years is forecast to increase by approximately 25%, giving 6-7,000 more over 75 year olds. Of these, 2,500 or so are forecast to be over 85 years. The minority ethnic population (6.3% 2001 Census) is also likely to increase and the age profile of this group, which is currently younger than the white population, will change. This will add to the increasing demand for services for older people.

Distribution of 65+ population

Population pyramid for
2010



Dudley population 2010-2020

The proportion of the population aged over 65 in Dudley is set to rise from 18.7% to 20.1% in 2015 and to 21.0% in 2020. This means that there will be an increase from 57,400 to 66,200 people over 65 in Dudley by 2020. The number of people aged over 85 is projected to increase by more than a third over the same time period.

How many people in Dudley are estimated to have Dementia?

The consensus estimates of the population prevalence (%) of late onset dementia

Estimated proportion people with dementia (dementia UK report, 2007)

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2

Age in years	Female	Male	Total
65-69	1.0%	1.5%	1.3%
70-74	2.4%	3.1%	2.9%
75-80	6.5%	5.1%	5.9%
80-84	13.3%	10.2%	12.2%
85-89	22.2%	16.7%	20.3%
90-94	29.6%	27.5%	28.6%
95+	34.4%	30.0%	32.5%

Estimated Numbers of people with late onset dementia in Dudley 2010-2020
(North East Public Health Observatory Mental health Briefing

<http://www.nepho.org.uk/search.php?s=16249&r=aHR0cDovL3d3dy5uZXRBoby5vcmVudWsvZ3NmLnBocDU/Zj03MDY=>

Dudley	2010			2015			2020		
Age Group	females	males	persons	females	males	persons	females	males	persons
65-69	86	122	208	94	135	229	86	123	209
70-74	182	211	393	197	223	420	214	251	465
75-79	403	250	653	436	286	721	475	311	786
80-84	625	337	962	665	367	1032	732	439	1170
85-89	632	253	884	643	292	935	694	346	1040
90-94	345	132	477	436	193	629	473	243	715
95+	133	32	165	148	46	193	199	74	273
total aged 65+	2407	1336	3743	2618	1541	4160	2871	1786	4657

Early Onset Dementia (<65 years)

Prevalence of Dementia by gender and age band (%) (ref MRC CFAS)

<http://www.cfes.ac.uk>

	30-64	65-69	70-74	75-79	80-84	85+
Males	0.07	1.4	3.1	5.6	10.2	19.6
Females	0.07	1.5	2.2	7.1	14.1	27.5

Estimated Numbers with Early Onset Dementia in Dudley, 2010-2020

Dudley	2010			2015			2020		
Age Group	females	males	persons	females	males	persons	females	males	persons
30-64	49	50	99	49	48	97	50	49	98

Dementia Prevalence by Type in Dudley, 2010-2020 (based on dementia UK)

Dudley	estimated	2010			2015			2020		
Dementia Type	%	females	males	persons	females	males	persons	females	males	persons
Alzheimer's disease	62%	1523	859	2382	1654	985	2639	1811	1138	2948
Vascular dementia	17%	417	236	653	453	270	724	496	312	808
Mixed dementias	11%	270	152	423	293	175	468	321	202	523
Lewy bodies	4%	98	55	154	107	64	170	117	73	190
Fronto Temporal dementia	2%	49	28	77	53	32	85	58	37	95
Parkinson's disease dementia	2%	49	28	77	53	32	85	58	37	95

The above Dementia UK suggested prevalence by Type does not reflect the prevalence in Dudley. The following is a breakdown over the last year (2011/12) of new patient diagnosis of dementia in Dudley:

Vascular dementia	117	50%
Mixed dementia	31	13.2%
Alzheimer's disease	77	33%
Frontal lobe/ CJD/Lewey Body	4	1.7%
Parkinson's disease dementia	5	2.1%

The high rate of vascular dementia is consistent with the Dudley Joint Strategic Needs Assessment and the high numbers of people with vascular disease in Dudley.

The Joint Commissioning Panel for Mental health have also noted in their commissioning guidance that the current evidence is that up to 50% of dementia cases may have a vascular component.

Dementia Estimates by Ethnic Group

Table: Estimated Numbers of People Aged 65+ with Dementia in Dudley

Ethnic Group	Estimated Number of people Aged 65+ with Dementia
White	3709
Mixed	5
Asian or Asian British	52
Black or Black British	28
Chinese or Other Ethnic Group	6
Total	3800

source: based on dementia prevalence estimates from dementia UK, 2007 & ONS mid year population estimates for 2009

Place of Residence

The Dementia UK report estimates that 60% of people with dementia live in their own homes, with 40% in nursing or residential homes. On this estimate, in Dudley, approximately 2300 people with dementia live at home.

Carers

- Much of the management of patients with dementia is indirect through the support of those caring for them. 30% of carers will suffer from depression at some stage, and information, emotional support and also practical support and respite services are essential.
- Many carers are themselves elderly people, and caring can pose a major burden affecting their own physical as well as mental health.

5. NATIONAL CONTEXT

The National Dementia Strategy (DH 2009) sets out a vision that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia, no matter what the stage of their condition or where they are in the health and social care system. This is in contrast to the current situation where in many services people with dementia are simply 'managed'.

In order to achieve this vision 17 objectives were identified specifying improvements in 3 key areas. Objectives 1 to 12 are grouped under 3 main headings to support a defined pathway for commissioning services

The National Dementia Strategy sets out clearly the case to ensure significant improvements are made to dementia services across three key areas:

- Improved awareness
- Earlier diagnosis and intervention
- Higher quality of care

The Dudley Dementia Awareness programme covers a range of activities to raise awareness and understanding of dementia in the borough with actions across all sectors. These activities will help to reduce stigma and challenge discriminatory behaviour, improve knowledge of signs and symptoms to aid early diagnosis, promote healthy lifestyles to reduce risk and support the agenda for living well with Dementia.

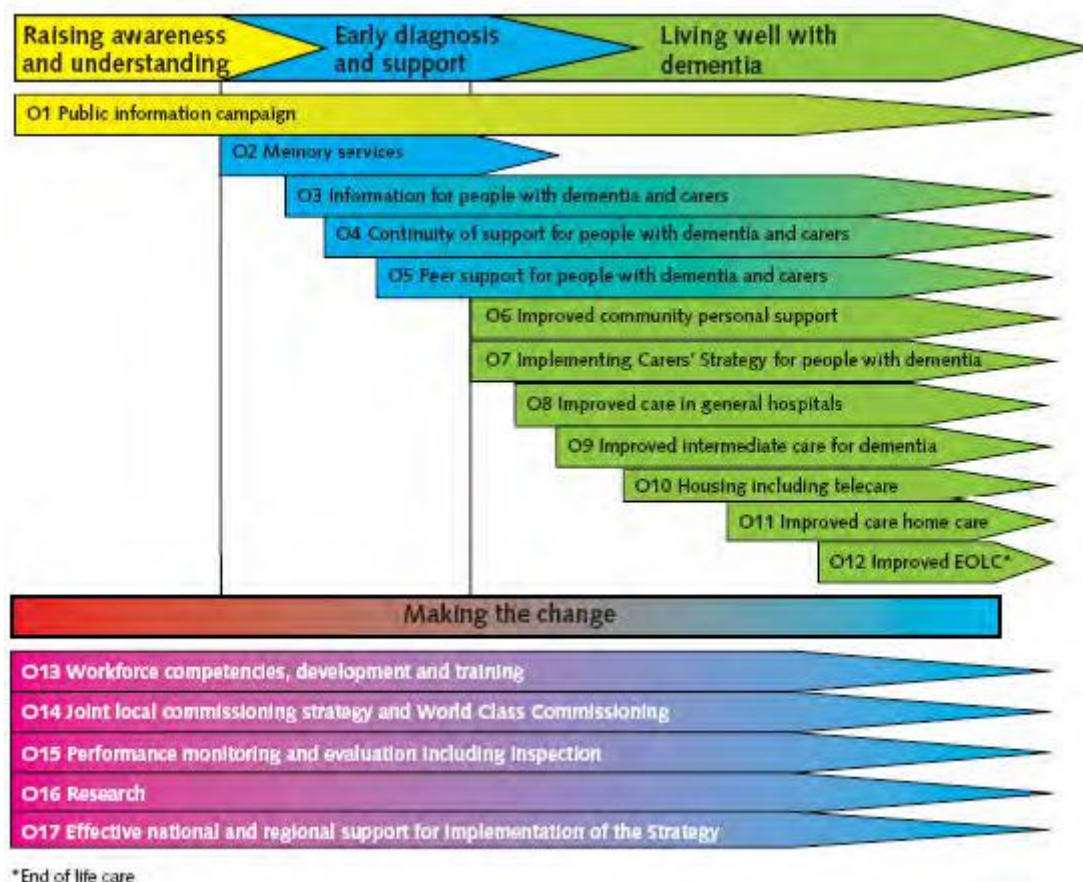
Successful awareness-raising can encourage earlier help-seeking from those who have concerns about dementia, more acceptance and greater inclusion within the community and importantly a more proactive community that is aware of potential risks to developing dementia.

Public health initiatives raise awareness of the importance of a healthy lifestyle highlighting the following key dementia prevention messages:

- **Keeping mentally active**
- **Eating a healthy diet**
- **Being physically active**
- **Being socially active**
- **Having regular health checks (BP, weight, cholesterol, blood sugar)**
- **Avoiding bad habits (don't smoke , drink sensibly and sleep well)**
- **Protect your head (head injury awareness)**

See **Appendix 1** for further information:

Figure ... Delivering the National Dementia Strategy - joint commissioning of services along a defined care pathway to enable people to live well with dementia²



The current government re-iterated its commitment to the needs of people living with dementia and their carers and in 2010 identified the implementation of the National Dementia Strategy as one of its priorities. This was reflected in a number of announcements and initiatives with the four priorities for dementia in being:-

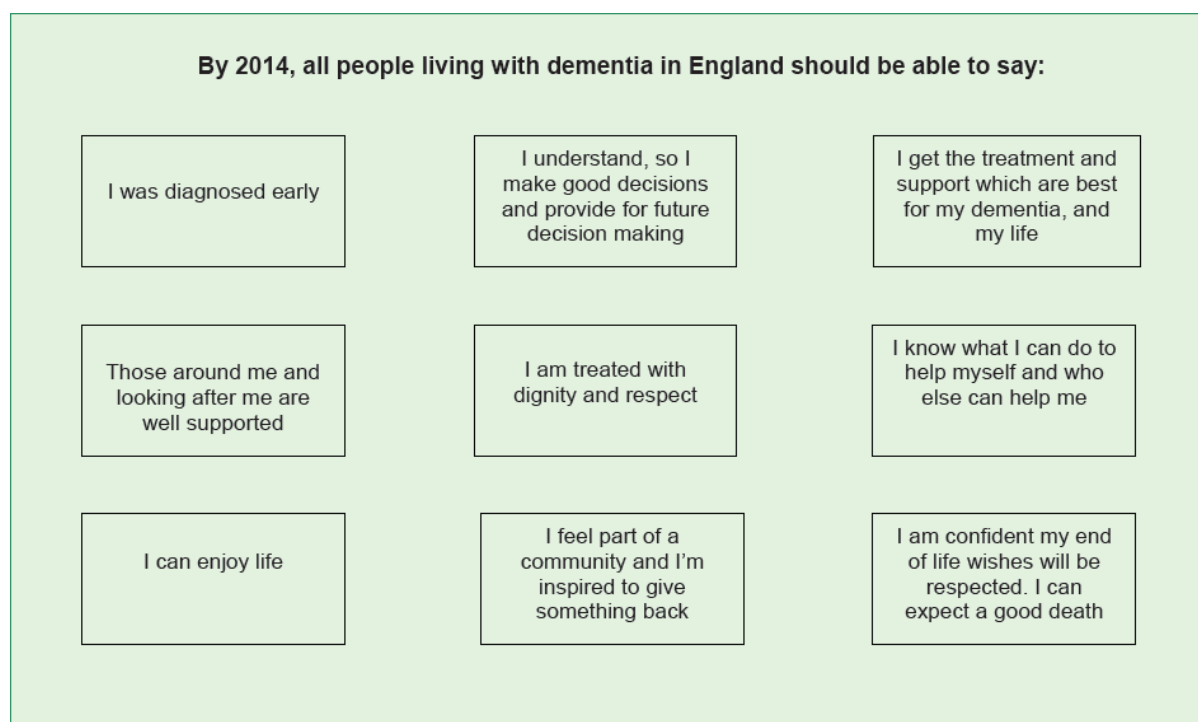
- **Good quality early diagnosis and intervention for all.** Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.
- **Improved quality of care in general hospitals.** 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.
- **Living well with dementia in care homes.** Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.
- **Reduced use of antipsychotic medication.** There are an estimated 180000 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 their prescription.

The Department of Health is working in consultation with partner organisations to identify key outcomes, which people with dementia and their carers expect. The Department will also be

developing specific, measurable indicators across health and social care, which underpin these outcomes, building on existing work such as the 2006 NICE/SCIE guideline, the NICE Quality Standard published in June 2010 and work undertaken by Alzheimer’s Society.

In line with established work in relation to cancer, the following nine statements have been proposed which capture what people with dementia tell us they aspire to in terms of their expectations of health and social care systems.

Fig 1 Draft synthesis of outcomes desired by people with dementia and their carers.



Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy*, Department of Health, September 2010

6. VIEWS of SERVICE USERS & CARERS

Public consultation event June 2012: Dementia Workshop

Are there any gaps or areas of concern to be addressed? (top 3 priorities)

1. GP consultant – gap too long
2. Carers support
3. Sharing info across health / LA

1. Prevention better than cure. If there is prevention – what is it that they can do?
Centre with stimulus where people come together suffering with dementia
Public awareness of dementia
2. Specialist training for those working in home and own homes (including carers)
3. What is difference between signs of old age and signs of dementia.
Emphasis on “care for the carer”

-
1. No mention of carers / family
 2. How to identify the “start” point for seeking help / self-diagnosis
 3. How to cope in early stages of dementia – as carer / as patients

1. Training / support for carer/family
 2. Support outside office hours
DWP / financial implications of dementia
 3. Level of understanding among GPs/
-

1. Staff I think should be monitored regularly to make sure that they are doing their job correctly. They should be monitored without knowing so you can see how they act when working.
2. Staff not being able to deal with a situation because they may feel scared / uncomfortable / unsure / not bothered
3. More in depth training and more practical's in training.

**Service user workshop September 4th 2012, Brettle Lane,
Dementia Gateway Centre**

PLEASE NOTE: The people who attended this workshop were in the majority carers of people diagnosed before the current pathway commenced in June 2011

Pre-diagnosis & Information

What have we got right

- Quicker diagnosis under new system?
- When put in touch with right consultant, system works
- GP knows about dementia
- Funding

What have we not got right

- Not being advised what to expect during diagnosis
- Only information available through self networking in groups
- GP's lack of information – not supportive.
- Person has deteriorated during diagnosis process due to how long it has taken
- No information leaflets in surgeries
- Attitudes of people – stigma – poor understanding
- No help for people if it seems they can manage
- People with health knowledge feeling like they have more information than professionals
- No one person/specialist to be referred to – different GP's – lack of continuity
- Knowledge and expertise to raise GP awareness – education
- Specialist GP to link to dementia – links to “who looks after me”
- Listen to carers – cement pathway – confidence to go to GP – its about the carer too
- Cultural change – mental health involvement
- Confidentiality can ‘fuzz’ access to information – who can I tell

- BME stigma attached to dementia
- Communication – not frightened to discuss – emotional support – right person to support

Priorities

- Transparency for person and carer – impact between authorities
- What is the journey – the pathway joined up – respite – impact on environment of carer
- What does help/support look like – “bank” hours between carers/volunteer (carers could look after someone else)
- Know the person and how to cope
- General information in public domain
- More information from Health – no general information available in surgeries.
- GP taking it seriously/taking notice/up to speed on condition
- Not getting to breaking point before support given – examples of people who felt they had to threaten to leave their relative to get support

Diagnosis

What have we got right

- Example of fast referral through Bushey Fields
- Access to expert by experience
- Peer support

What have we not got right

- Need to know the process
 - Speak to someone before beginning the diagnosis route
 - Remove the stigma
 - Communication in an informal comfortable community setting
 - Getting through the day to manage in the here and now
 - Once diagnosed, if medication is not needed initially no follow up – automatic assumption that they will be able to cope
 - Non acceptance of family/friends regarding diagnosis
- Little support for carer in diagnosis process

Priorities

- Access to support
- Support for person needed – information/advice/counselling
- Support for carer needed – reassurance/counselling/services
- Follow up to diagnosis is important
- Not leaving people to their own devices
- Is two specialist nurses enough – No
- Timely diagnosis and time to ask
- Prognosis afraid to ask for the long term effect – process to share information
- Information regarding dementia

Ongoing Care

What have we got right

- Identify self as a carer to promote information
- Support through dementia advisors
- Excellent social worker
- Excellent mental health nurse
- Alzheimer's Society support

What have we not got right

- Where is the publicity to point to expertise and help
- Establish what carer needs
- Support Planning
- Named support person
- Getting more information from other carers than professionals
- Biggest help from Charities – no formal services
- Not knowing what questions to ask (due to previous lack of information)
- Having to take people to GP – rather than home visit – when this is really difficult

Priorities

- Information – so knowing what to ask for – need help but don't know what is available
- More person centred services – visiting GP's and hospitals with person with dementia is really difficult
- Big difference when you have 'good' social worker/nurse but this isn't universal
- Back up for carer need if things go wrong (support services/Home Care/Direct Payments)
- Dementia friendly communities needed.
- What is the support – how to access
- Respite – what is it – where - how to access – frequency
- Cost – who pays/how much what is a personal budget

Crisis Situations

What went right

- Respite is beneficial
- Good to use same place if possible
- Small things supportive in respite make all the difference i.e. clothes coming back washed
- Carers emergency card
- Carer may have to make treatment decision – health versus trauma of treatment

What have we not got right

- Having to get to crisis point before support is available
- Very stressful on carer during these times with no carer support
- Fairness in respite booking system
- Respite in Bushey Fields awful – no activity or support promoted.
- Care of pets

Priorities

- Carer support in crisis for relative – where to go if not in formal services
- Easy access to preferred respite and emergency respite

- Easier to find support for relative in crisis than carer in crisis – this should be better
- Cover via some services is available if people know about it.
- Palliative care – who are they, where are they – nurses/Home Care
- Suitable care in homes
- Support for carers – groups – who to contact – talk to someone (end of phone/peer support) - volunteers
- Care buddies
- Home Safety
- Manage situation discreetly
- Wills/Power of attorney

CONCLUSION

An earlier version of this strategy was approved for consultation by the Dudley Mental Health Board and Dudley Older People's Board for consultation in late 2012 and early 2013. The document was widely discussed across the health economy including Dudley Health and Overview and Scrutiny Committee, Dudley MBC, Dudley Clinical Commissioning Group, Dudley Alzheimer's Society and within the Dudley Dementia Gateways.

The emerging theme was to translate the objectives into actions for delivery. This is now captured in appendix 1 for what the members of the Dudley dementia Strategy Group need to implement. The strategy group will continue to meet to ensure actions are implemented, monitor progress and that there are positive outcomes for people with dementia and their carers.

There has been highly productive partnership working over the last 3 years on dementia. The Dudley dementia strategy group with its wide membership has been central to discussing and achieving the changes and particularly the input from service users and carers. However, there is no time for complacency and achieving the objectives particularly in ensuring more people access services will be of the highest priority for commissioners and health/social care professionals.

Appendix 1

7. DELIVERING THE DUDLEY DEMENTIA STRATEGY

The following sections sets out how in Dudley we will respond and act to the objectives set out in the nine quality outcomes above the National Dementia Strategy (DH 2009), NICE Quality Standards for Dementia (2010), Joint Commissioning Panel for Mental Health (2012), David Cameron dementia challenge 2012.

Objective	What we have in place	What we need to deliver	What we will do	Outcomes
<p>1/ Improving public and professional awareness and understanding.</p> <p>David Cameron dementia challenge. A service should have:</p> <p>National criteria for delivery</p> <p>1.1 Explains what people and their carers should expect from local dementia services across all parts of the person's journey, linked to NICE quality standards</p> <p>1.2 Describes the specific local 'offer' for dementia services commissioned by</p>	<p>Information leaflets via Dementia Gateways</p> <p>Combined approach with Dudley Alzheimer's Society and Dudley MBC Gateway centres. MBC has a marketing plan that takes a phased approach to avoid being inundated on services.</p> <p>Public health initiatives have taken place in schools to raise awareness of dementia.</p> <p>GP education programme delivered in December 2012</p> <p>Awareness via www.dudley.nhs.uk/emotionalhealth</p> <p>See appendix 2 for further initiatives</p>	<p>A general public information campaign linked to both national and local initiatives with public health involvement</p> <p>Targeted approach via the vascular health checks</p> <p>To ensure there are further links to dementia in the public health website</p> <p>To ensure the dementia services are known to the hard to reach groups such as those with a loss of hearing, homeless people and travellers.</p>	<p>Deliver the MBC marketing strategy for Dementia Gateways.</p> <p>Link with sensory support organizations e.g. Beacon Centre for the Blind to promote services.</p> <p>Ensure there is more awareness of Dudley dementia services via the 'Life channel' in GP practices</p>	<p>Raised awareness of types of dementia and support/service opportunities that are available</p>

<p>the local NHS and the local authority</p> <p>1.3 Provides a directory of local organisations that deliver services throughout the person's journey. This gives the organisation the opportunity to describe what it provides.</p> <p>1.4 Presents comparisons of local organisations that enable people to understand the performance of their health and social care services, with the opportunity for organisations to comment on their own results.</p> <p>1.5 Provides opportunities for people to ask questions via an online forum and feedback on services they have received.</p>				
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<p>2/ To prevent dementia via public health initiatives Preventing onset of dementia is important, given there is currently no cure. Current evidence is that up to 50% of dementia cases may have a vascular component (i.e. vascular or mixed dementia)</p>	<p>Highlighting the potential risk factors for dementia (these include hypertension, heavy alcohol use and smoking) and ensuring primary care services are involved in preventative work.</p> <p>Cerebrovascular health promotion:-</p> <ul style="list-style-type: none"> • Improved diet, lifestyle interventions and take-up of health checks are likely to reduce dementia rates 	<p>To include in education programmes across primary, community and secondary care.</p> <p>Identification of people with dementia in the community:</p> <p>GPs should take the opportunity to review patients that they see regularly for other conditions, such as heart disease, diabetes, asthma and hypertension. Early identification of mild cognitive impairment, and other symptoms that may indicate onset of dementia, will enable the patient to receive an early diagnosis and appropriate advice and support.</p> <p>To include in local QOF indicators</p> <p>To include screening as part of vascular health checks</p>	<p>Improve awareness on the links to excessive alcohol and dementia.</p> <p>Further GP education</p>	<ul style="list-style-type: none"> • Reduce dementia risk as a consequence of reduction in vascular disease • Earlier access to support, advice and information, as a consequence of earlier identification of dementia
<p>3/ Good quality early assessment, diagnosis and intervention for all Rapid and competent assessment leading to an accurate diagnosis and appropriate treatment, care and support Improving diagnosis –</p>	<p>Dudley's dementia assessment, diagnosis and intervention service are to:</p> <ul style="list-style-type: none"> • promote and facilitate early identification and referral and encourage eligible patients to attend for assessment • provide a high quality, accurate diagnosis of dementia that is 	<p>Increase the number of people diagnosed with dementia to meet the England average benchmark</p> <p>With many of the anti-dementia medications coming off patent and potential new guidance for vascular dementia there could be</p>	<p>The CCG has as one of its Quality Premiums for 2013/14 a focus on increasing the number of people diagnosed with dementia and has invested in additional workforce of the</p>	<ul style="list-style-type: none"> • An increase in the proportion of people with dementia receiving a formal diagnosis compared with the local

<p>including early diagnosis – is a gateway to more effective dementia care and support. High quality assessment, diagnosis and intervention services for people with mild and moderate dementia should have the following characteristics. They should:</p> <ul style="list-style-type: none"> • make the diagnosis well • communicate the diagnosis well • provide appropriate treatment (medication, psychological and behavioural), information, care and support following diagnosis. 	<p>communicated in a person centred way to the person with dementia and to their carers and meets their individual needs</p> <ul style="list-style-type: none"> • ensures that people with dementia and their carers are given information so they can manage their care more effectively along the pathway, understand how to access other help and make practical arrangements for the future • involve people with dementia and their carers in decisions about the care options available to them, including the development of individual care plans. <p>Dementia guidelines have been developed and implemented for GPs</p> <p>Dudley Group of Hospitals have a focus and screening for vascular dementia</p>	<p>an increase in referrals for anti-dementia medications http://www.bap.org.uk/pdfs/Anti-dementia_2010_BAP.pdf</p>	<p>specialist dementia service to meet the increase in referrals.</p> <p>Shared care protocols are in place for anti-dementia medication to ensure accessibility for all that meet the criteria and need. The number of prescriptions to be monitored on a monthly basis</p> <p>Monitoring via questionnaires of the people accessing services to ascertain experiences of care.</p>	<p>predicted prevalence (NICE quality standard 2 –</p> <ul style="list-style-type: none"> • An increase in the proportion of people with dementia receiving a diagnosis when they are in the mild stages of the illness (NICE quality standards 1, 3, 4) • An increase in the number of patients and carers who have a positive experience of health care services • Reduced risk of crises later in the course of the illness. • Early identification and treatment can also extend the
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				<p>period of time that the person with dementia can live and be cared for at home, if this is what they want.</p> <p>The cost savings of early diagnosis are estimated to be around £2,685 per person diagnosed. These savings derive mainly from extending the time that someone can be cared for in the community, before they need to be admitted to a nursing home</p>
<p>4/ Good quality information for those diagnosed with dementia and their carers</p> <p>Providing good quality information on dementia and available services both at diagnosis and throughout illness</p>	<p>Good quality information on dementia and available services</p> <p>(see appendix 1)</p>	<p>To develop a local website specific to dementia and local services</p> <p>Yearly up-dates and reviews of existing information</p>	<p>DMBC: Making it Real</p> <p>Adding dementia to the Dudley Dementia Community Information Directory.</p> <p>To include a depository of information (council directory)</p>	<p>To ensure that people with dementia, their families, friends and carers have access to good quality information that is informative and supportive to better health</p>

			To link with NHS choices Embedding links to Health watch to improve standards, advocacy and sign-posting	gains and maintaining independence or where to go to if help is needed.
5/ Enabling easy access to care, support and advice following diagnosis Dementia advisers to facilitate easy access to care, support and advice following diagnosis	Dementia Advisors have been appointed and are based in the dementia gateway centre plus a further advisor based in the hospital. Every person now diagnosed with dementia across Dudley is appointed/offered a dementia advisor who will be there to support throughout their illness	Link dementia advisor into acute hospital and carers unit. All Advisors to undertake low level social care assessments	All Dementia Advisors to be fully competent in social care assessment Nov 2013	More people supported to live at home and/or the preferred place of care.
6/ Development of structured peer support and learning networks Providing support to people with dementia and their carers and enabling them to take an active role in local service development and prioritisation	The three Dementia Gateway Centres provide practical and emotional support, reduce social isolation and promote self-care. Expert Patient Programmes run concurrently throughout the year for carers of people with dementia. New dementia café's and Alzheimer's café's are being progressed across Dudley. Education is further provided by the	An expert patient programme for people with mild dementia. To further develop peer support networks via the dementia café's and incorporate in the Dudley Alzheimer's service level agreement. Patient and Carers to be represented on the Dementia Strategy Group.	planning to involve people with dementia and their carers influence development and strategy	More people accessing support networks across Dudley

	Dudley Alzheimer's Society (see also specific information re above in appendix/sections further on)			
7/ Improved community personal support services Providing an appropriate range of services to support people with dementia living at home with their carers	The aim of supporting patients with dementia (and their carers) at home is to ensure they maintain independence and a high quality of life Range of services including respite commissioned via Dudley MBC dementia gateway centres and Dudley Alzheimer's Society. Further dementia cafes in development. Outreach support and respite is provided via the Dudley Dementia Gateways and the Dudley Alzheimer's Society.	To monitor and evaluate services that provide support to those with a diagnosis of dementia and their carers	To develop Dementia Friendly Communities: linked to Dementia Alliance Action Plans: 2013-2015	Quality Outcomes addressed as per Figure 1 above
8/ Prescribing anti-dementia medication to deliver the current local guidance on treatment with anti-dementia drugs	There is appropriate access to the recommended medications for treating dementia via the pathway and referral to the older adults psychiatrists at DWMHT.	To audit/monitor the number of people each month that commence anti-dementia medication and their reviews and the duration of treatment. With many of the anti-dementia medications coming off patent and potential new guidance for vascular dementia there could be an increase in referrals for anti-dementia medications http://www.bap.org.uk/pdfs/Anti-dementia_2010_BAP.pdf	To include activity of prescribing in the DWMHT contract for older adults	Access to anti-dementia medications is one of the key benefits of assessment and early diagnosis. These medications may improve cognitive functioning, reduce behaviours that carers find

		To consider other specialist to initiate and review people requiring anti-dementia medication		challenging and, alongside other early interventions, improve independent living and delay entry to long-term nursing home care.
<p>9/ Monitoring the inappropriate use of anti-psychotic medication</p> <p>A key national dementia policy goal is a reduction in the inappropriate use of antipsychotic medication to treat older people with dementia. Of particular concern has been the high level of inappropriate antipsychotic use in care homes. Antipsychotic medications are helpful to treat psychosis and some cases of aggression and severe agitation. However, antipsychotic medications have been commonly prescribed for behaviours such as restlessness, agitation and loss of inhibition, where the evidence for their benefits is weak.</p>	Local audit implemented CQUIN within DWMHPT for anti-psychotic prescribing (adherence to formulary)	<p>To audit/monitor the number of people each month that commence anti-psychotic medication with a diagnosis of dementia and their reviews and the duration of treatment.</p> <p>To ensure alternative therapies and non-pharmacological solutions are offered other than anti-psychotic medications including access to IAPT.</p> <p>DGHFT have added to the checklist any patients on anti-dementia medication.</p>	<p>To develop the creative therapeutic activities in Gateways and extend via 'lifelong learning' to carer homes across Dudley.</p> <p>To have a CPN for residential and nursing homes across Dudley to work with staff and enhance their personal and management skills</p> <p>To develop 'Dementia Care Mapping' in care homes and other community environments.</p>	To reduce the need for anti-psychotic medications

<p>10/ Commissioning specialist Dementia services</p> <p>The primary care team managing patients with dementia will need access to support and advice from specialist mental health care services in the following areas:</p> <ul style="list-style-type: none"> • making complex diagnoses • managing patients with co-morbid functional mental health problems • managing patients with behaviours that challenge • managing patients with extremely challenging behaviours who are putting themselves and others at risk • using appropriate medications other than anti-psychotic drugs to help manage a patient with dementia (see also medication objectives) 	<p><u>Dudley Walsall Mental Health Trust:</u></p> <ul style="list-style-type: none"> • Day centres • In-patient services including beds • Community mental health teams for older people • Respite • Crisis services 	<p>To provide expert advice and treatment in the management of patients in their own homes or appropriate care settings, and offer specialist advice on the prescription of antipsychotics and other medication for people with dementia.</p> <p>The service will include care home liaison on a pro-active, in-reach basis to prevent inappropriate admissions to hospital.</p> <p>As well as interventions for individual referrals, the service will provide education, training and coaching to care home staff to enable them to recognise, prevent and manage challenging behaviours more effectively. The team should also work closely with the hospital liaison service to facilitate rapid and smooth discharge from hospital in-patient beds. There is a clear evidence base for such services.</p> <p>The service will ensure that carers are appropriately assessed and have access to the treatment and support they need.</p> <p>The team will provide specialist support to primary care.</p> <p>People with dementia who</p>	<p>To finalize and implement the service specification and contract for older adults mental health (that includes dementia)</p> <p>To improve management of people with co-morbidities the dementia register to be accessed by DWMHT, Dudley Group and WMAS.</p>	<p>An increase in the proportion people with dementia that are accessing specialist dementia services.</p>
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		<p>develop non-cognitive symptoms causing significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating/aggravating factors. Interventions to improve behaviour or distress should be recorded in their care plan.</p> <p>To commission and develop a dementia service specification.</p>		
11/ Supporting people at working age of dementia	All dementia services in Dudley are age inclusive both in health and social services.	<p>To provide appropriate respite services in-conjunction with a Black County approach</p> <p>To ensure early diagnosis for this group of people</p>	The MBC are looking at the development of hubs for working age dementia that are linked to the Gateways and Dementia Cafes.	More people with dementia of working age accessing appropriate services.
12/ Implementing the Carers' Strategy for people with dementia Carers have a right to an assessment of their needs and can be supported through an agreed plan which will include personalised breaks. Children in caring roles should also be supported	<p>All carers of people diagnosed with dementia are offered a carers assessment via the Dementia Gateways.</p> <p>Dementia Advisors are undertaking screening for those carers who may need a more comprehensive assessment by a social worker</p> <p>Carers respite is provided via the gateways and Dudley Alzheimer's Society.</p> <p>District Nurses undertake a carers</p>	To be more robust in the Quality Outcomes Framework that GPs are checking that carers have had a carers assessment and identify carers to be offered a health check.	<p>To ensure that more people can access the 'Looking After Me' course</p> <p>To ensure that more people know of, and are able to access, support such as that offered through Carers Network, Carers Groups, Carers Emergency plans, Carers Direct payments</p>	To ensure that more carers looking after someone with a diagnosis of dementia are supported and able to access services including maintenance of their own health.

	<p>assessment using the Carer Stress/Strain Index as per their service specification</p> <p>Other carers support include</p> <ul style="list-style-type: none"> -Carers Direct payments for those unable to fund a break -Carers Emergency plans - - Supporting people initiative to support carers at an early stage 			
<p>13/ Improved quality of care for people with dementia in general hospitals and mental health liaison services for dementia</p> <p>Identifying leadership, defining care pathways and commissioning specialist mental health teams in general hospitals</p> <p>Up to 70% of hospital beds are occupied by older people</p> <ul style="list-style-type: none"> • up to half of these may be people with cognitive impairment, including • dementia and delirium • when people with dementia are admitted 	<p>Senior clinician has been identified to take the lead for quality improvement in dementia in a hospital</p> <p>Education and training staff on care and awareness of dementia.</p> <p><u>Adherence to CQUIN:</u></p> <p>A/ to improve awareness and diagnosis of dementia, using risk assessment in an acute setting. These indicators cover dementia screening, dementia risk assessment and referral for specialist diagnosis</p> <p>B/Education and training plans for staff in the hospital</p> <p>C/ Engagement of carers of people with dementia in discharge planning.</p> <p>Early Supported Discharge form</p>	<p>Implementing the New Cross Hospital led work on the Composite for dementia care</p> <p>Adherence to CQIN schemes for screening people for dementia and reviews of anti-psychotic medication</p> <p>To ensure services are in place to support people with dementia admitted to hospital.</p>	<p>Early plans in place for a dementia unit within the existing bed base and also for wider environmental changes.</p> <p>Trialling dementia care bundles on C3 currently and will review via the Elderly Care QPDT process with a view to roll out Trust wide</p> <p>Dementia has been made a LTC Transformation Project by the Trust</p>	<p>Reductions in unplanned admissions and re-admissions to acute and psychiatric hospitals from home/care homes</p> <ul style="list-style-type: none"> • reduction in antipsychotic medication use for people with dementia in care homes/other residential settings • increase in the number of patients and carers who have a positive experience of hospital care, and fewer complaints

<p>for treatment of other conditions, they stay in hospital longer than people with the same condition but without dementia.</p> <p>Acute mental health liaison services provide:</p> <ul style="list-style-type: none"> • support and advice on assessment and diagnosis • support and advice on care planning and behaviour management • access to other available specialist supports • support to staff training and • organisational development 	<p>Russells Hall Hospital to support patients with mild to moderate dementia</p> <p>Dementia Advisor now working at Dudley Group of Hospitals</p>			<ul style="list-style-type: none"> • reduction in the number of patients discharged directly from hospital to care homes as a new place of residence
<p>14/ Improved intermediate care for people with dementia</p> <p>Providing suitable and accessible intermediate care</p>	<p>Dudley has 24 beds in total that can be accessed for dementia patients. This includes a dedicated unit of 6 beds in Tiled House</p> <p>In addition the community (LIT) team would also accept patients (provided there was some rehab/recuperation potential).</p> <p>We are also looking at dementia provision within intermediate care –</p>	<p>To ensure there is increased provision within intermediate care</p> <p>Recent scoping work has recommended an additional 6 bed capacity and therefore we are looking at commissioning extra capacity which will be flexible and responsive to patients with dementia.</p>	<p>The CCG is working closely with the Local Authority (via the Integrated Care group) to ensure a flexible provision of Intermediate Care for patients with dementia. Additional capacity is being created by the redesign of existing services and this is</p>	<p>More people to be cared for in their own homes via the provision of intermediate care</p>

			expected to be in place for winter 2013.	
<p>15/ Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers</p> <p>Commissioners should consider the options to prolong independent living and delay reliance on more intensive services</p>	<p>Two extra care housing schemes now with places for people with dementia are now up and running in Dudley</p> <p>Telecare services are integrated with dementia gateway centres and this includes a 'Gadget Gateway' that allows people to see the technology that is available.</p> <p><u>Dudley Housing has embarked on Extra care housing that includes specific places for people with dementia.</u></p> <p><u>Dementia –Tele care-health</u> Dudley have implemented the automated pill dispenser pilot. Other tele-care to support dementia care Door exit sensors, temperature extreme, flood detectors, memo minders, magi plugs, life style monitoring, GPS watch, bed sensor, enuresis sensor, calendar clock, talking clock, smoke detector, night light, pressure mat, chair sensor and passive infra Red detectors</p>	<p>Establish a watching brief over the emerging evidence base on assistive technology and telecare. To develop a tele-health project group to include a practitioner with mental health skills.</p> <p>Develop skills of staff working within housing</p>	<p>To develop supportive activities for people living within extra care housing schemes for people with dementia.</p>	<p>More people to remain independent in the community via accessing tele-care and housing support initiatives.</p>
<p>16/ Living well with dementia in care homes</p>	<p>Training courses in place for care home staff to care for people with</p>	<p>Increased education and training courses/support for care home</p>	<p>To develop a new role of a community</p>	<p>Improved quality of care for</p>

<p>Improving quality of care by defining leadership and care pathways, commissioning specialist mental health teams and through inspection regimes</p>	<p>dementia.</p> <p>New Dudley Care Home Programme will include supporting care home staff caring for people with dementia and challenging behaviour. To include dedicated RMN to form part of an ANP team for care homes</p> <p>Review of appropriate use of anti-psychotics</p>	<p>staff</p> <p>Increased contacts from specialist mental health teams in care homes</p> <p>Increasing access to homes that can offer specialist care for people with dementia including those with challenging behaviour.</p>	<p>psychiatric nurse for dementia to work within the Dudley NHS care home team. This will include teaching, education and supporting staff in homes.</p>	<p>residents in care homes</p> <p>Reduction in inappropriate secondary care admissions</p>
<p>17/ Improved end of life care for people with dementia Adhere to Department of Health's End of Life Care Strategy</p>	<p>Dedicated palliative care nurses for care homes. To work more closely with new care home team and RMN. Protocols and advanced care plans in development for end of life care and dementia. To develop dementia register to include end of life care indicators.</p>	<p>Ensuring that palliative care networks, developed as part of the End of Life Care Strategy, support the spread of best practice on end of life care in dementia</p> <p>Developing better pain relief and nursing support for people with dementia at the end of life</p> <p>Develop better end of life care using the planning tools in the Mental Health Capacity Act</p> <p>Improve referrals to palliative care team and end of life care pathways for dementia consistent with the Gold Standard Framework</p> <p>To implement the advanced care plans</p>	<p>To ensure that palliative care services are in place and extended to those with a diagnosis of dementia</p> <p>There is a commitment to the 'transforming end of life care' project in Dudley which will reinforce the principles of supporting people in their preferred place of care. The joint end of life care strategy is also due for a refresh at the end of this year so further plans will develop from this.</p>	<p>More people supported at end of life in their preferred place of care.</p>

<p>18/ To ensure appropriate access for services for people with sensory impairments (visual and auditory)</p>	<p>Dementia nurses and advisors have good awareness and understanding of assessing people with sensory impairments</p> <p>Referral systems in place for Dudley hearing and visually impaired services</p> <p>Loop systems in place</p>	<p>To raise and increase awareness of dementia services for people with sensory impairments</p>	<p>For the Dementia Gateways to develop links with the Beacon Centre for the Blind particularly with advice, guidance and aids.</p>	<p>More people with a sensory impairment are able to access services and have confidence in the provision of service to meet their needs</p>
<p>19/ An informed and effective workforce for people with dementia Providing effective basic training and development to health and social care staff</p>	<p>Training in place for care homes staff, community and across departments at Dudley Group of Hospitals.</p> <p>GP education programme on dementia to commence in December 2012</p> <p>Dementia Care Mapping implemented via Dudley MBC</p> <p>Training to commence in autumn 2012 on Care Fit for VIPS across residential and nursing homes. This is based on the nationally recognised VIPS Framework of Dementia Care.</p>	<p>Identify core competencies required in dementia care</p> <p>Adapt training as required</p> <p>Commissioners to specify necessary dementia training for service providers</p> <p>Improve continuing staff education in dementia such as the dignity champions mental health and older people presentation.</p> <p>Review national health and social care standards</p>	<p>To develop training for primary care staff practice nurses.</p> <p>To link into the National Dementia friends and Champions Initiative</p>	<p>More health and social care staff are trained in the care and management of people with services and are able to support, refer and signpost people with dementia and their carers to appropriate services.</p>
<p>20/ Support for people with learning disabilities and dementia People with learning disabilities are at higher</p>	<p>Dementia pathway for people with learning disabilities in place in Dudley (see appendix 3 for current services)</p>	<p>To ensure liaison services are in place to support people with learning disabilities and dementia admitted to hospital.</p>	<p>Develop a pathway via The Learning Disabilities Acute Liaison Nurse (appointed July 2013)</p>	<p>All people with a LD are referred into the LD pathway for dementia and</p>

<p>risk than the general population of developing dementia before the age of 65 and people with Down's syndrome are particularly affected.</p>	<p>People with LD are accessing the Dudley Dementia Gateways</p>		<p>to manage the interface between hospital, primary care and community specialist learning disability services for patients with LD and dementia needing acute hospital care.</p>	<p>receive appropriate services.</p>
<p>21/ To ensure all dementia services are accessible for those people from Black and minority ethnic groups living with dementia.</p>	<p>Translation services are available for all staff caring for people with dementia.</p> <p>Dementia Awareness training delivered to a cross section of representatives from minority ethnic community groups across the borough to improve recognition of signs and symptoms , reduce stigma and promote early presentation.</p> <p>Dementia Awareness Project commissioned to identify specific local needs within Halesowen Asian Elders and their carers.</p>	<ul style="list-style-type: none"> • Public Health Programmes to engage with BME communities on dementia issues, services and the Dudley Dementia Strategy • Public Health department to receive dementia awareness training • Areas for potential joint working to be identified • A successful piece of work with Halesowen elders could be replicated in other towns and areas across Dudley 	<p>Delivery of the Dudley MBC and Public Health Action Plan for BME communities</p>	<p>Raised awareness among BME groups of dementia services and increased numbers of people with dementia from BME groups are able to access services.</p>

<p>22/ Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers</p> <p>Improving inspection regimes for care homes and other services</p>	<p>Inspection regimes via Dudley MBC and CQC.</p> <p>New local monitoring pilot completed for 'Positive Assurance' to include dementia and rolled out across Dudley.</p>	<p>To ensure the new Dudley Care Home Forum takes a cross health economy approach and the CQC to improve standards and safeguarding in care homes</p>	<p>To continue Appreciative enquiry visits to care home to help to identify areas of good practice and areas which require improvement in care for patients with dementia</p>	<p>Improved quality of care for residents in care homes</p>
<p>23/ A clear picture of research evidence and needs</p> <p>Detailing the existing UK research base for dementia, and the gaps within</p>	<p>Dudley is complying with NICE guidance and national best practice. More research evidence required to substantiate practices.</p>	<p>To ensure that Dudley has a strong evidence base of dementia that guides the delivery of future services</p>	<p>To ensure implementation of evidence based research/practice and develop links with Worcester University dementia department for example evaluation of therapeutic activities.</p>	
<p>24/ Effective national and regional support for implementation of the Strategy</p> <p>Appropriate national and regional support to be available to advise and assist local implementation. The Department of Health will provide support for all those involved in implementing the strategy locally to ensure its</p>	<p>CCG Commissioner attends regional meetings</p> <p>MBC Manager attends meetings with West Midlands MBC leads</p>	<p>To ensure that Dudley has representation/links on regional networks and the support teams to support local implementation</p>	<p>To request reconvening the West Midlands Clinical Group for dementia</p>	

<p>delivery, particularly for those areas where services are less developed.</p> <p>A national baseline measurement of services will be established</p> <p>Information will be gathered on an annual basis to review the extent of services</p> <p>There will be specifically commissioned research, evaluation and data to support implementation</p>				
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Appendix 2

Actions from Public Health to Support Dementia Awareness

Context:

DELIVERING THE NATIONAL DEMENTIA STRATEGY

Objective 1: Improving Public Awareness and Understanding: *Improving the perception of Dementia in the wider society and reducing the stigma attached*

WEST MIDLANDS QUALITY REVIEW FOR DEMENTIA SERVICES

Quality Standard KZ-102

Commissioners should ensure that a ‘Dementia awareness’ programme is run, targeted at the public, schools and key voluntary and statutory organisations. This programme should cover prevention, early identification and where to go for further information.

The following table demonstrates actions taken by Public Health to support this campaign.

ACTIVITY	TIMESCALE
Public Health lifestyle services information made available to Dementia advisors via commissioner to sign post patients or carers to Public Health lifestyle programmes to improve quality of life of people with dementia and their carers.	April 2011
Dementia training provided to Health Trainer’s manager to cascade to staff who engage with members of the public to raise awareness of dementia prevention messages, signs and symptoms and sign posting to GP.	April 2012
Dementia Awareness article in Public Mental Health quarterly e-bulletin distributed on 20 th May 2012 (to over 400 contacts from local voluntary and statutory organisations in the borough) for <i>National Dementia Week</i> 20-26 th May with details of condition signs and symptoms, prevention messages (Vascular risk factors etc), local and national support organisations and signposting to local clinical services and Dementia Gateways.	May 2012
Cascaded Dementia resources for use in PHSE tutorials to secondary schools PHSE leads in Dudley borough	June 2012
A two page article on Dementia prevention, signs, symptoms and services published in the ‘ <i>together</i> ’ magazine produced by local authority which is distributed throughout Dudley Borough.	July 2012

ACTIVITY	TIMESCALE
<p>Raised awareness of Dementia agenda amongst Public Health staff through the promotion of Dementia training resources (on line) for public facing workforce to cascade dementia awareness information (particularly vascular risk factors) to the general public at health events, appointments etc around the following key prevention strands:</p> <ul style="list-style-type: none"> ○ Keeping mentally active ○ Eating a healthy diet ○ Being physically active ○ Being socially active ○ Having regular health checks (BP, weight, cholesterol, blood sugar) ○ Avoiding bad habits (don't smoke , drink sensibly and sleep well) ○ Protect your head (head injury awareness) <p>Information also given regarding local service provision and signposting.</p>	<p>September 2012</p>
<p>Halesowen Asian Elderly Association commissioned to deliver a Mental Health Promotion ‘Small Grant Fund Project’ to raise awareness of Dementia in minority ethnic communities</p>	<p>May 2013</p>
<p>National contact details for Alzheimer’s Society and Age UK available on Emotional Health and Wellbeing (Public Health) website www.dudley.nhs.uk/emotionalhealth and in self help mental health promotion resources available through Dudley Public Health. Develop further links to dementia via public health website.</p>	<p>Ongoing</p>
<p>Dementia awareness resources ‘Understanding Dementia’ (Mind) and Dudley Dementia service provision leaflets disseminated at community health events by Public Mental Health team across the borough.</p>	<p>Ongoing</p>
<p>Get into Reading (GIR) social outreach pilot delivered by Dudley Libraries for 12 weeks in Rye Villa Dementia Care home 2011. Facilitator lead sessions engaging with literature in group setting to improve social activity and Quality Of Life of dementia sufferers.</p>	<p>Ongoing (Sessions to continue on a monthly basis throughout 2012)</p>
<p>Exploring targeted Dementia screening as part of the Vascular Health Checks Programme.</p>	<p>Ongoing</p>

ACTIVITY	TIMESCALE
<p>For further information please contact:</p> <p>Dudley Public Health Public Mental Health Team Jamie.annakin@dudley.nhs.uk</p> <p>August 2012</p>	

Appendix 3

Older People and Learning Disabilities Black Country Partnership Foundation Trust

What is a Learning Disability?

People with Learning Disabilities are not an homogenous group. However, there are a number of features of learning disability which have gained widespread acceptance across professional boundaries within the UK.

1. A substantial intellect deficit (actual or estimated IQ of below 70) coexisting with:
2. Significant deficits in adaptive/social functioning (communication, self-help, domestic, health and safety, applied academic, leisure and work skills and:
3. Occurring before the age of 18.

All three criteria must be met for a person to be considered to have a Learning Disability

Prevalence rates and presentation of dementia among people with learning disabilities with and without Down's syndrome

People with Down's syndrome make up 15% of all people with learning disabilities. There has been a dramatic increase in life expectancy such that more than 50% will live beyond 50 years of age. In adults with Down's syndrome, the prevalence of dementia is between 10% to 25% for those between 40-49 years of age, 20% to 50% in those between 50-59, and between 30% to 75% 60 years of age. Therefore, people with Down's syndrome are at high risk of developing dementia at a much earlier age. Average onset is approximately 50, with death after onset on average at 58 years.

Dementia can present atypically in people with Down's syndrome. Behavioural and/or personality changes, rather than functional memory decline can be the early signs of developing dementia some years before the full clinical picture of dementia. Memory and orientation are reported as being affected early, with language, visuo-spatial skills and praxis becoming affected later in the disease process.

For those with other forms of learning disability without dementia, the prevalence is also higher, with reports of over 13% at 60 years and over 18 % at 65 years. This compares to 1% of 60 to 65 year old and 13% 80 to 85 year olds in the general population.

Learning Disability Dementia Service (Dudley Borough)

Aims: To provide specialist clinical services for older people with a learning disability in Dudley Borough; specifically to aid in the diagnosis and development of clinical interventions for older people with a learning disability and dementia. Specifically the service provides:

- Early assessment of dementia to facilitate focused support and adaptation of service provision to enable a person to be maintained within their home and current service provision.
- Individualised assessment and clinical interventions for clients when dementia is suspected or who may already have a diagnosis of dementia.
- Specialised advice, consultation and supervision on psychological issues, needs and care of clients, with particular responsibility for those who have been identified as having dementia.
- Proactive baseline assessment for those considered to be at highest risk or where concerns are noted.
- Training regarding issues related to dementia to carers/family and staff including training on early identification of age related changes.

- Clients, carers and services with access to clear information and sources of support for carers.
- Support to services regarding risk assessment where an individual service or others, may be at risk as a result of dementia.
- Support to day and residential services to develop the ability to rapidly and flexibly adapt to the onset of dementia, and provide appropriate interventions, packages of care and specialist support that can enable them and/or their carers in maintaining independence within their own homes or day placements wherever possible, should their intellectual and social functioning be deteriorating.

Referral into Learning Disability Dementia Service Pathway

Referrals to the service are considered on the basis of whether:

- The person is over the age of 18 years, who live in the Dudley borough and/or who are registered with a Dudley GP.
- The referred person has a learning disability defined above.
- The referrer has concerns that the person has shown early signs of dementia. These include:

Changes in memory

Changes in finding the right words or understanding what people are saying

Changes in mood, personality, behaviour, mobility

Changes in ability to complete self-care/domestic tasks and solve small problems

Changes in ability to learn new things

- In addition, referral for baseline screening for all adults with Down's syndrome over 35 years of age, (with or without early signs concerns), is advised to establish a baseline to compare future suspected changes in functioning.

The service is available between 9:00 a.m. and 5:00 p.m. on weekdays, with some flexibility to meet identified client needs on a case by case basis. Referrals to the Dementia Service are accepted on an open referral system. The Learning Disability Dementia Service Co-ordinator will clarify if the person is known to the service and the Special Needs Register (SNR). If the person is unknown but has a learning disability diagnosis, a referral to the Community Learning Disability Teams (CTLD) will be considered. Contact with the CTLD will be made to establish others who may be involved with the client and to ensure they are involved throughout the care pathway. This will facilitate appropriate support to be made available following assessment, intervention and recommendations.

If a referral is not appropriate for the Learning Disability Dementia Service, a letter will be sent to the referrer and copied to the GP and CTLD, stating reasons with advice/onward referral to the generic older adult services pathway as appropriate.

For referral or further information, please contact:

**The Learning Disability Dementia Service
The Ridge Hill Centre
Brierley Hill Road
Stourbridge**

Tel: 01384 323558