







# **Living Well with Dementia**

# **A Dementia Strategy for Dudley**

2012-2015

## **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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#### **Foreword**

In the last year there has been considerable investment and redesign of dementia services across Dudley.....

#### 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.

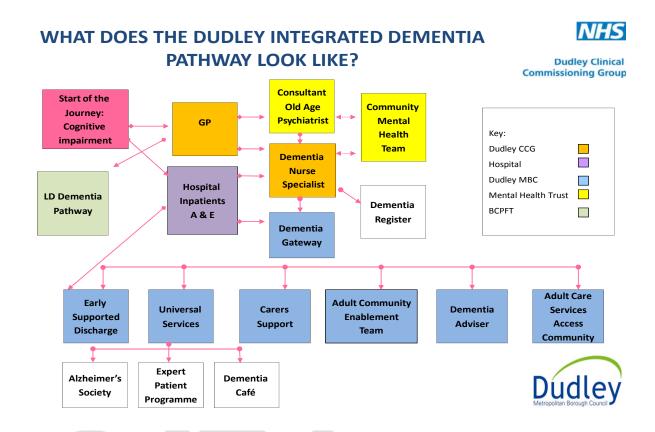
The Strategy is designed to be inclusive of all citizens in Dudley including those of working age. It is also inclusive of all user groups including for example, adults who may have a learning disability or other long term health conditions that impact on their cognitive abilities.

<sup>1</sup>http://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

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

<sup>4</sup> 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.



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

#### Consultation

Following approval from the Dudley Mental Health Board and Dudley Older People's Board the draft strategy will be circulated for a period of 12 weeks consultation.

- Service User Involvement
- Consultation on commissioning decisions

The draft Strategy will be released for consultation on Monday October 29<sup>th</sup> and we have posed a series of questions on which we would particularly like the views of interested parties but of course we would also welcome comments on the whole document.

In addition we would ask for views on the relative priority that should be attached to different proposals

The consultation period will run from October 29<sup>th</sup> 2012 to January 21st 2013 and comments should be sent to:

Dementia Strategy Consultation

C/O Andrew Hindle
Dudley CCG
St John's House
Union Street
Dudley, DY2 8PP

#### 2. VISION

#### **Our Vision**

NHS and Social Care services in Dudley seek to commission a high quality, integrated and evidence based dementia service for older 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 coordinated 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.

### Question 1/ Do you agree with this vision?

#### 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.

<u>Vascular dementia</u> – 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.

<u>Alzheimer's disease</u> –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.

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

<u>Fronto-temporal</u> – 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

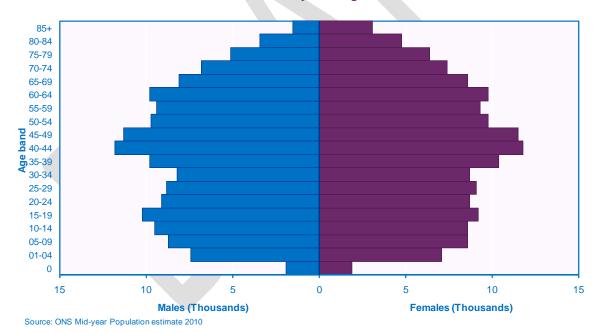
In Dudley in 2010, 57,400 people out of a total population of 307,500 are estimated to be over 65 (18.7%).

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 Borough Residents**



#### **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=aHR0cDovL3d3dy5uZXBoby5vcmcudWsvZ3NmLnBocDU/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.cfas.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.

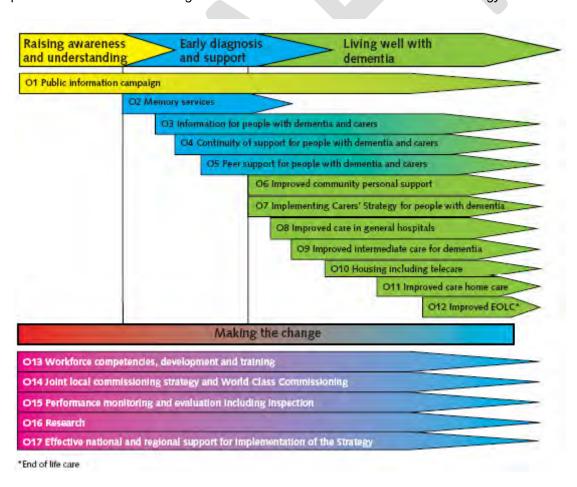
Public health initiatives raise awareness of the importance of a healthy lifestyle highlighting the following key dementia prevention messages:

- Keeping mentally active
- Eating a healthy diet
- Being physically active
- o Being socially active
- Having regular health checks (BP, weight, cholesterol, blood sugar)
- o 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

<sup>2</sup>Department of Health 2009 Living Well with Dementia – A National Dementia Strategy



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
- 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
- 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 with out 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 4<sup>th</sup> 2012, Brettle Lane, <u>Dementia Gateway Centre</u>

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

- ldentify 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 then home visit when this is really difficult

#### **Priorities**

- ➤ Information so knowing what to ask form 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

### Question 2/ Do you think this reflects your experiences?

(Health Professionals) Is this your perception of the user experience?

#### 7. DELIVERING THE DULDEY 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	Outcomes
Improving public and	Information leaflets via Dementia	A general public information campaign	Raised awareness of types of
professional awareness	Gateways	linked to both national and local	dementia and support/service
and understanding.		initiatives with public health involvement	opportunities that are available
	Combined approach with Dudley		
David Cameron dementia	Alzheimer's Society and Dudley MBC	Targeted approach via the vascular	
challenge. A service should	Gateway centres. MBC has a	health checks	
have:	marketing plan that takes a phased		
National criteria for delivery	approach to avoid being inundated on	To ensure there are further links to	
<ol> <li>Explains what</li> </ol>	services.	dementia in the public health website	
people and their			
carers should expect	Public health initiatives have taken	GP education programme to be	
from local dementia	place in schools to raise awareness of	delivered in December 2012	
services across all	dementia.		
parts of the person's		To ensure the dementia services are	
journey, linked to	Awareness via	known to the hard to reach groups such	
NICE quality	www.dudley.nhs.uk/emotionalhealth	as those with a loss of hearing,	
standards		homeless people and travellers.	
<ol><li>Describes the</li></ol>	See appendix 1 for further initiatives		
specific local 'offer' for	11		
dementia services			
commissioned by the			
local NHS and the			
local authority			
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.  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.  5. Provides opportunities for people to ask questions via an online forum and feedback on services they have received.			
people to ask questions via an online forum and feedback on services			
,			
To prevent dementia via public health initiatives	Highlighting the potential risk factors for dementia (these include	To include in education programmes across primary, community and	reduced dementia risk as a consequence of reduction in
Preventing onset of dementia	hypertension, heavy alcohol use and	secondary care.	vascular disease
is important, given there is	smoking) and ensuring primary care		<ul> <li>earlier access to support,</li> </ul>
currently no cure. Current	services are involved in preventative	Identification of people with dementia in	advice and information, as a
evidence is that up to 50% of	work.	the community:	consequence of earlier
dementia cases may have a			identification of dementia
vascular component (i.e.	Cerebrovascular health promotion:-	GPs should take the opportunity to	

vascular or mixed dementia)	Improved diet, lifestyle interventions and take-up of health checks are likely to reduce dementia rates	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.  To include in local QOF indicators  To include screening as part of vascular health checks	
Good quality early assessment, diagnosis and	Dudley's dementia assessment, diagnosis and intervention service are	With many of the anti-dementia	an increase in the proportion of people with dementia
intervention for all Rapid and competent assessment leading to an accurate diagnosis and appropriate treatment, care and support Improving diagnosis — 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: • make the diagnosis well	<ul> <li>promote and facilitate early identification and referral and encourage eligible patients to attend for assessment</li> <li>provide a high quality, accurate diagnosis of dementia that is communicated in a person centred way to the person with dementia and to their carers and meets their individual needs</li> <li>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</li> </ul>	medications coming off patent and potential new guidance for vascular dementia there could be an increase in referrals for anti-dementia medications <a href="http://www.bap.org.uk/pdfs/Anti-dementia">http://www.bap.org.uk/pdfs/Anti-dementia</a> 2010 BAP.pdf	receiving a formal diagnosis compared with the local predicted prevalence (NICE quality standard 2 –  • 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

communicate the diagnosis well     provide appropriate treatment (medication, psychological and behavioural), information, care and support following diagnosis.	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.  Dementia guidelines have been developed and implemented for GPs		treatment can also extend the period of time that the person with dementia can live and be cared for at home, if this is what they want.  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
Good quality information	Good quality information on dementia	To develop a local website specific to	To ensure that people with
for those diagnosed with	and available services	dementia and local services	dementia, their families, friends
dementia and their carers			and carers have access to good
Providing good quality	(see appendix 1)	Yearly up-dates and reviews of existing	quality information that is
information on dementia and		information	informative and supportive to
available services both at			better health gains and
diagnosis and throughout illness			maintaining independence or where to go to if help is needed.
IIIICOO	Dementia Advisors have been	Link dementia advisor into acute hospital	More people supported to live at
Enabling easy access to	appointed and are based in the	and carers unit.	home and/or the preferred place
care, support and advice	dementia gateway centres.		of care.
following diagnosis			
Dementia advisers to	Every person now diagnosed with		
facilitate easy access to care,	dementia across Dudley is		
support and advice following	appointed/offered a dementia advisor		
diagnosis	who will be there to support throughout		
Development of atmostrate	their illness	An aypart nation programme for papels	Mara paople accepting average
Development of structured peer support and learning	The three Dementia Gateway Centres provide practical and emotional	An expert patient programme for people with mild dementia is being	More people accessing support networks across Dudley
networks	support, reduce social isolation and	commissioned later in 2012.	Hetworks across Dudley
HELWOLKS	support, reduce social isolation and	COMMINISSIONED INICI III ZUTZ.	

Providing support to people with dementia and their carers and enabling them to take an active role in local service development and prioritisation	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.	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.	
	Education is further provided by the Dudley Alzheimer's Society  (see also specific information re above in appendix/sections further on)		
Improved community personal support services Providing an appropriate range of services to support people with dementia living at home with their carers	in appendix/sections further on)  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	Quality Outcomes addressed as per Figure 1 above
Prescribing anti-dementia	There is appropriate access to the	To audit/monitor the number of people	Access to anti-dementia
medication to deliver the current local	recommended medications for treating dementia via the pathway and referral	each month that commence anti- dementia medication and their reviews	medications is one of the key benefits of assessment and

			7
guidance on treatment with	to the older adults psychiatrists at	and the duration of treatment.	early diagnosis. These
anti-dementia drugs	DWMHT.		medications may improve
		With many of the anti-dementia	cognitive functioning, reduce
		medications coming off patent and	behaviours that carers find
		potential new guidance for vascular	challenging and, alongside other
		dementia there could be an increase in	early interventions, improve
		referrals for anti-dementia medications	independent
		http://www.bap.org.uk/pdfs/Anti-	living and delay entry to long-
		dementia 2010 BAP.pdf	term nursing home care.
		dementia 2010 BAI .pdi	term narsing nome care.
		To consider other specialist to initiate	
		and review people requiring anti-	
BB 14 1		dementia medication	
Monitoring the		To audit/monitor the number of people	
inappropriate use of anti-	CQUIN within DWMHPT for anti-	each month that commence anti-	
psychotic medication	psychotic prescribing (adherence to	psychotic medication with a diagnosis of	
A key national dementia	formulary)	dementia and their reviews and the	
policy goal is a reduction in		duration of treatment.	
the inappropriate use of			
antipsychotic medication to			
treat older people with		To ensure alternative therapies and non-	
dementia. Of particular		pharmacological solutions are offered	
concern has been the high		other than anti-psychotic medications	
level of inappropriate		including access to IAPT.	
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 ovidence		T	Г
inhibition, where the evidence for their benefits is weak.			
	Dudley Wolcoll Montal Hoolth Trust	To provide expert advice and treatment	An increase in the properties
Commissioning specialist Dementia services	Dudley Walsall Mental Health Trust:	To provide expert advice and treatment in the management of patients in their	An increase in the proportion people with dementia that are
	Day control		
The primary care team	Day centres	own homes or appropriate care settings,	accessing specialist dementia services.
managing patients with dementia will need access to		and offer specialist advice on the prescription of antipsychotics and other	Services.
	In-patient services including	medication for people with dementia.	
support and advice from specialist mental health care	beds	The service will include care home	
services in the following		liaison on a pro-active, in-reach basis to	
areas:	Community mental health	prevent inappropriate admissions to	
making complex	teams for older people	hospital.	
diagnoses	Daarita	As well as interventions for individual	
	Respite	referrals, the service will provide	
managing patients with co-morbid functional	Origin complete	education, training and coaching to care	
mental health problems	Crisis services	home staff to enable them to recognise,	
managing patients with		prevent and manage challenging	
behaviours that		behaviours more effectively. The team	
challenge		should also work closely with the hospital	
<ul> <li>managing patients with</li> </ul>		liaison service to facilitate rapid and	
extremely challenging		smooth discharge from hospital in-	
behaviours who are		patient beds. There is a clear evidence	
putting themselves and		base for such services.	
others at risk		The service will ensure that carers are	
using appropriate		appropriately assessed and have access	
medications other than		to the treatment and support they need.	
anti-psychotic drugs to		The team will provide specialist support	
help manage a patient		to primary care.	
with dementia (see also			
medication objectives)		People with dementia who 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 helpsylicis	
		Interventions to improve behaviour or distress should be recorded in their care	
		plan.	
		Pidit.	
		To commission and develop a dementia	
		service specification.	
Supporting people at	All dementia services in Dudley are	To provide appropriate respite services	More people with dementia of
working age of dementia	age inclusive.	in-conjunction with a Black County	working age accessing
		approach	appropriate services.
		To ensure early diagnosis for this group	
Implementing the Carers'	All carers of people diagnosed with	of people  To be more robust in the Quality	To ensure that more carers
Strategy for people with	dementia are offered a carers	Outcomes Framework that GPs are	looking after someone with a
dementia	assessment via the Dementia	checking that carers have had a carers	diagnosis of dementia are
Carers have a right to an	Gateways.	assessment and identify carers to be	supported and able to access
assessment of their needs	- Caromayor	offered a health check.	services including maintenance
and can be supported	Carers respite is provided via the		of their own health.
through an agreed plan which	gateways and Dudley Alzheimer's		
will include personalised	Society.		
breaks. Children in caring			
roles should also be	District Nurses undertake a carers		
supported	assessment using the Carer		
	Stress/Strain Index as per their service specification		
Improved quality of care for	Senior clinician has been identified to	Implementing the New Cross Hospital	Reductions in unplanned
people with dementia in	take the lead for quality improvement	led work on the Composite for dementia	admissions and re-admissions to
general hospitals and	in dementia in a hospital	care	acute and psychiatric hospitals
mental health			from home/care homes
liaison services for		Adherence to CQIN schemes for	
dementia	Education and training staff on care	screening people for dementia and	reduction in antipsychotic
l	and awareness of dementia.	reviews of anti-psychotic medication	medication use for people with
Identifying leadership,	A II		dementia in care homes/other
defining care pathways and	Adherence to CQUIN to improve	To ensure liaison services are in place	residential settings
commissioning specialist	awareness and diagnosis of dementia,	to support people with dementia	increase in the number of

mental health teams in using risk assessment in an acute admitted to hospital. patients and carers who have a general hospitals setting. These indicators cover positive experience of hospital dementia screening, dementia risk care, and fewer complaints Up to 70% of hospital beds assessment and referral for specialist reduction in the number of patients discharged directly from diagnosis. are occupied by older people hospital to care homes as a new Early Supported Discharge form place of residence Russells Hall Hospital to support up to half of these may patients with mild to moderate be people with cognitive dementia to commence in August impairment, including 2012. dementia and delirium when people with dementia are admitted for treatment of other conditions, they stay in hospital longer than people with the same condition but without dementia. Acute mental health liaison services provide: 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 **Improved intermediate care** Dudley has 24 beds in total that can be To ensure there is increased provision More people to be cared for in

for people with dementia Providing suitable and accessible intermediate care	accessed for dementia patients. This includes a dedicated unit of 6 beds in Tiled House  In addition the community (LIT) team would also accept patients (provided there was some rehab/recuperation potential).  We are also looking at dementia provision within intermediate care —	within intermediate care  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.	their own homes via the provision of intermediate care
Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers  Commissioners should consider the options to prolong independent living and delay reliance on more intensive services	Two extra care housing schemes now with places for people with dementia are now up and running in Dudley  Telecare services are integrated with dementia gateway centres  Dudley Housing has embarked on Extra care housing that includes specific places for people with dementia.  Dementia –Tele care-health 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,	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.  Develop skills of staff working within housing	More people to remain independent in the community via accessing tele-care and housing support initiatives.

Living well with dementia in care homes Improving quality of care by defining leadership and care pathways, commissioning specialist mental health teams and through inspection regimes	enuresis sensor, calendar clock, talking clock, smoke detector, night light, pressure mat, chair sensor and passive infra Red detectors  Training courses in place for care home staff to care for people with dementia.  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	Increased education and training courses/support for care home staff Increased contacts from specialist mental health teams in care homes Increasing access to homes that can offer specialist care for people with dementia including those with challenging behaviour.	Improved quality of care for residents in care homes  Reduction in inappropriate secondary care admissions
	Review of appropriate use of antipsychotics		
Improved end of life care for people with dementia Adhere to Department of Health's End of Life Care Strategy	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	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  Developing better pain relief and nursing support for people with dementia at the	More people supported at end of life in their preferred place of care.
	indicators.	end of life  Develop better end of life care using the planning tools in the Mental Health Capacity Act  Improve referrals to palliative care team and end of life care pathways for dementia consistent with the Gold Standard Framework	

		To implement the advanced care plans	
To ensure appropriate access for services for people with sensory impairments (visual and auditory)	Dementia nurses and advisors have good awareness and understanding of assessing people with sensory impairments  Referral systems in place for Dudley hearing and visually impaired services  Loop systems in place	To raise and increase awareness of dementia services for people with sensory impairments	More people with a sensory impairment are able to access services and have confidence in the provision of service to meet their needs
An informed and effective workforce for people with dementia Providing effective basic training and development to health and social care staff	Training in place for care homes staff, community and acute hospital.  GP education programme on dementia to commence in December 2012  To consider training for primary care staff practice nurses.  Dementia Care Mapping implemented via Dudley MBC  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.	Identify core competencies required in dementia care  Adapt training as required  Commissioners to specify necessary dementia training for service providers  Improve continuing staff education in dementia such as the dignity champions mental health and older people presentation.  Review national health and social care standards	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.
Support for people with learning disabilities and dementia People with learning disabilities are at higher risk than the general	Dementia pathway for people with learning disabilities in place in Dudley (see appendix 2 for current services)		All people with a LD are referred into the LD pathway for dementia and receive appropriate services.

population of developing dementia before the age of 65 and people with Down's syndrome are particularly affected.  To ensure all dementia services are accessible for those people from Black and minority ethnic groups living with dementia.	Translation services are available for all staff caring for people with dementia.  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.  Dementia Awareness Project commissioned to identify specific local needs within Halesowen Asian Elders and their carers.	<ul> <li>Public Health Programmes to engage with BME communities on dementia issues, services and the Dudley Dementia Strategy</li> <li>Public Health department to receive dementia awareness training</li> <li>Areas for potential joint working to be identified</li> </ul>	Raised awareness among BME groups of dementia services and increased numbers of people with dementia from BME groups are able to access services.
	and their carers.		
Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers Improving inspection regimes for care homes and other services	Inspection regimes via Dudley MBC and CQC. New local monitoring pilot completed for 'Positive Assurance' to include dementia and rolled out across Dudley.	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	Improved quality of care for residents in care homes
A clear picture of research evidence and needs Detailing the existing UK	Dudley is complying with NICE guidance and national best practice. More research evidence required to	To ensure that Dudley has a strong evidence base of dementia that guides the delivery of future services	

research base for dementia,	substantiate practices.		
and the gaps within			
Effective national and	<u> </u>	To ensure that Dudley has	
regional support for	meetings	representation/links on regional networks	
implementation of the		and the support teams to support local	
Strategy		implementation	
Appropriate national and			
regional support to be		A'	
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			
delivery, particularly for those			
areas where services are			
less developed.			
A national baseline			
measurement of services will			
be established			
Information will be gathered			
on an annual basis to review			
the extent of services			
There will be specifically			
commissioned research,			
evaluation and data to			
support implementation			

# Summary of proposals and commissioning intentions to address in **Dudley**

Question 3/ Do you think these objectives will meet the needs

of people with dementia and their families and

carers?

Question 4/ Is there anything additional in the detailed

proposals that you would like to see or anything

not required?

#### IN CONCLUSION

We have asked some specific questions and asked for your views on a variety of areas. If there are any other issues you would like to comment on, please do so in the space provided on the executive summary or the consultation response document.

Question 5/ Are there any other comments or issues that you would like to add?

#### **Appendix 1**

### **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 <sup>th</sup> May 2012 (to over 400 contacts from local voluntary and statutory organisations in the borough) for <i>National Dementia Week</i> 20-26 <sup>th</sup> 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 'together' magazine produced by local authority which is distributed throughout Dudley Borough.	July 2012

ACTIVITY	TIMESCALE
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:	
Keeping mentally active	
<ul> <li>Eating a healthy diet</li> </ul>	
Being physically active	September 2012
Being socially active	
<ul> <li>Having regular health checks (BP, weight, cholesterol, blood sugar)</li> </ul>	
<ul> <li>Avoiding bad habits (don't smoke, drink sensibly and sleep well)</li> </ul>	
Protect your head (head injury awareness)	
Information also given regarding local service provision and signposting.	
Halesowen Asian Elderly Association commissioned to deliver a Mental Health Promotion 'Small Grant Fund Project' to raise awareness of Dementia in minority ethnic communities	May 2013
National contact details for Alzheimer's Society and Age UK available on Emotional Health and Wellbeing (Public Health) website <a href="https://www.dudley.nhs.uk/emotionalhealth">www.dudley.nhs.uk/emotionalhealth</a> and in self help mental health promotion resources available through Dudley Public Health. Develop further links to dementia via public health website.	Ongoing
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.	Ongoing
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.	Ongoing (Sessions to continue on a monthly basis throughout 2012)
Exploring targeted Dementia screening as part of the Vascular Health Checks Programme.	Ongoing

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



#### Appendix 2

## 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 Coordinator 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