

Dementia Strategy August 2008 Version 1.3

1. Purpose

This strategy sets out the direction of travel for services for people in South Staffordshire suffering from dementia, and their carers. It proposes the establishment of a specific outcome focussed 'care pathway' for dementia and the development of new services which will assist the rapidly growing number of people who suffer from this terrible ailment to live with its consequences with enhanced quality and control in their lives. This strategy runs from 2008 to 2012, but needs to be seen in the context of the rapid increase in dementia in our ageing population over these years and inexorably beyond. Dementia is now being given greatly increased local and national attention and rightly so, as the misery which the condition creates is a huge and increasing part of society and the demands which it makes on health and social care have the potential to be devastating for services and budgets. The strategy is based on the premises that people with dementia and their carers want and will benefit from early and continued support, much of which can be at a relatively low level; that health and social care need to work in partnership with each other, with people with dementia and their carers, and with community and voluntary sector partners; information, early diagnosis, planning in partnership and continued available support through to end of life care can make the management and impact of this long term condition much more feasible, and reduce the levels of long term care home and hospital support needed.

2. Introduction

Dementia is a chronic or persistent disorder of behaviour and higher intellectual function due to organic brain disease. Symptoms of dementia include impairment of attention, orientation, memory, judgment, language, motor and spatial skills and function. The majority of people who are diagnosed with dementia have either Alzheimer's disease or vascular dementia, or a combination of the two.

Dementia is close to us all: either in our older age, or looking to it, we know that 1 in 20 people aged 65 have dementia with the number rising to 1 in 4 over the age of 85 years. The total number of people with dementia in the U.K is forecast to increase to 1 million by 2021 and nearly 2 million by 2051. This represents an increase of 38% over the next 13 years and 154% over the next 43 years.

Dementia is a devastating long term condition and, for those suffering from it and their carers and families, it has a distressing, debilitating and all encompassing effect. In addition, the annual economic burden for the country has been assessed as more than £14 billion - greater than stroke, cancer and heart disease combined.

Most of this impact is on carers and other family members, but the national annual cost to the NHS and social care is estimated to be £3.3 billion. Yet it is often not diagnosed, or is dismissed by professionals as an inevitable part of ageing.

50 – 80% of older people in care homes have dementia, but two thirds of people with dementia live in the community. There is no known cure, and representations have been made about the relatively low levels of funding in research. For South Staffordshire, there are over 7,000 people suffering from it now, but by 2017 that will be over 10,000 and by 2027 over 13,000. This inexorable growth needs to be matched by improvements in services and their co-ordination. The increasing proportion of older people in the population in the years ahead is a national phenomenon, but certain parts of South Staffordshire will experience a significantly greater increase in the older population, with consequently greater need for services.

Currently there is no provision of a dedicated 'Dementia service'. This leads to many unnecessary challenges and issues for people with dementia and their carers. These include lack of access to appropriate and timely services, lack of access to treatment, lack of continuity within and between a range of services and service providers, inconsistencies between funding sources during the disease journey and lack of advanced care planning. A noticeable absence of any advanced care planning is evident for end of life care for people with dementia. It is particularly important to start such decision making processes while people with dementia have capacity.

In essence this is a reactive focus to care which leads to crisis situations which could be prevented, and which often result in inappropriate use of unscheduled care.

Current service provision spans primary care, healthcare trusts, social care, the acute sector, voluntary, and independent sectors. These providers deliver elements of a range of services for those with mental health needs and for older people's needs. Funding sources vary and there is no overarching coordination of services for people with dementia across their disease journey.

Links between services for those with dementia who have other long term conditions or general increasing frailty are poor and staff are generally ill equipped to address behavioural changes in general settings and physical issues in mental health settings.

This document has been produced by the Staffordshire Joint Commissioning Unit, with the detailed involvement of several partners from the NHS, Social Care and Health and the voluntary sector in the related work as members of the Service Improvement Board, and the underlying support of the South Staffordshire Dementia Network. The dementia SIB has been working for a shorter time than some other SIBs and a clinical champion – Dr Ian Greaves - has only recently been appointed. This

strategy belongs to a point in time – as explained below, the publication of the national strategy is likely to have an impact, and there is more detailed work to be done on mapping current activity and funding, the costs of service change (the estimated costs in the proposals at the end of this strategy require more detailed work) and the monitoring and evaluation systems to accompany implementation.

The strategy has been strongly influenced by the consultation draft National Dementia Strategy (2008), which is expected to be launched in its final version in October 2008, and therefore the implementation of this strategy will evolve as that document is published and government expectations are made clear – optimistically, with additional funding to enable implementation. The work has also been greatly assisted by the West Midlands SHA NHS Next Stage Review : Report of Dementia/Long Term Conditions/ End of Life Clinical Pathway Group (2008). A more detailed needs and service gap analysis is available in ‘South Staffordshire older people’s mental health: assessment of needs and services’ published by South Staffordshire PCT and Staffordshire County Council (March 2008).

The dementia SIB has undertaken this work as part of the group’s wider review of the needs of older people presenting the full spectrum of mental health problems, and this should not be forgotten in focussing on dementia. For example, depression is experienced by over 40% of people over 85 and suicide rates are particularly high among older people. The table below shows just how prevalent depression is and also the frequency with which depression is associated with Alzheimer’s Disease and with being a carer for someone with dementia.

Table 1: The prevalence of depressive disorder in older people across settings and conditions:

Setting / Condition	Prevalence
Older people receiving home care from social services (1)	26%
Carers of dementia sufferers (2)	28%
Acute medical inpatients (3)	23%
GP attendees (4)	37%
Older people in residential care homes (5)	17%
Older people who are new residents in residential and nursing homes (6)	45%
Older people with Parkinson’s Disease (7)	40%
Older people with Alzheimer’s Disease (8)	20%
Older people post stroke (9)	23%
Older people with cancer (10)	25%
Older people with hip fracture (11)	Up to 47%
Older people after MI (12)	31%
Older people with congestive heart failure (13)	59%
Older people with chronic obstructive pulmonary disorder (14)	40%

(1) Banerjee and MacDonald 1996; (2) Coope et al 1995; (3) Burn et al 1993; (4) Evans and Katona 1993; (5) Neville et al 1995; (6) Godlove Mozeley et al 2000; (7) Cummings and Masterman 1999; (8) Allen and Burns 1995; (9) Burvill et

Older people with mental health needs have been relatively disadvantaged in that the funding, organisational and service requirements and targets for adult mental health have not applied to older people and there is a huge gap to be filled; all mental health services for older people are starting from a relatively very low base.

Older people may often suffer from physical conditions and increasing frailty as well as mental ill health. Any services for people with dementia must be able to take account of co-morbidities; and of course, dementia is not suffered only by older people – for about 2.5% of people with dementia, its onset occurs when they are under pensionable age and people with a learning disability are particularly liable to develop dementia, often at a relatively early age.

3. Vision and proposed pathway

These have been taken from the West Midlands report; they have the support of the local dementia SIB and have the benefit of being designed as a blueprint and best practice model which can be used across the West Midlands and are compatible with the thinking in the national dementia strategy development to date. We recognise the proposed pathway is at this stage aspirational: investment and service change will need to be developed along the way in order to realise this aspiration. In time, the development of a distinct dementia service, which recognises and supports the 'long term condition' nature of dementia, will be dependent upon a re-evaluation of other services for older people with mental health needs and how these are provided; for example, with a distinct dementia service, are the needs of older people with functional mental ill health best met within an all embracing older people's mental health service, which includes a dementia long term conditions service, or by an extension and development of adult mental health services? - but this is not an issue addressed in this strategy. This strategy focuses on the development of dementia services only, but recognises that their development forces the need to address the above question soon.

Our vision

By 2012 all people with a suspected or confirmed diagnosis of dementia will access an integrated, seamless, proactive and high quality locality based service that encompasses all the expertise to meet needs of the people with dementia and those of their carers.

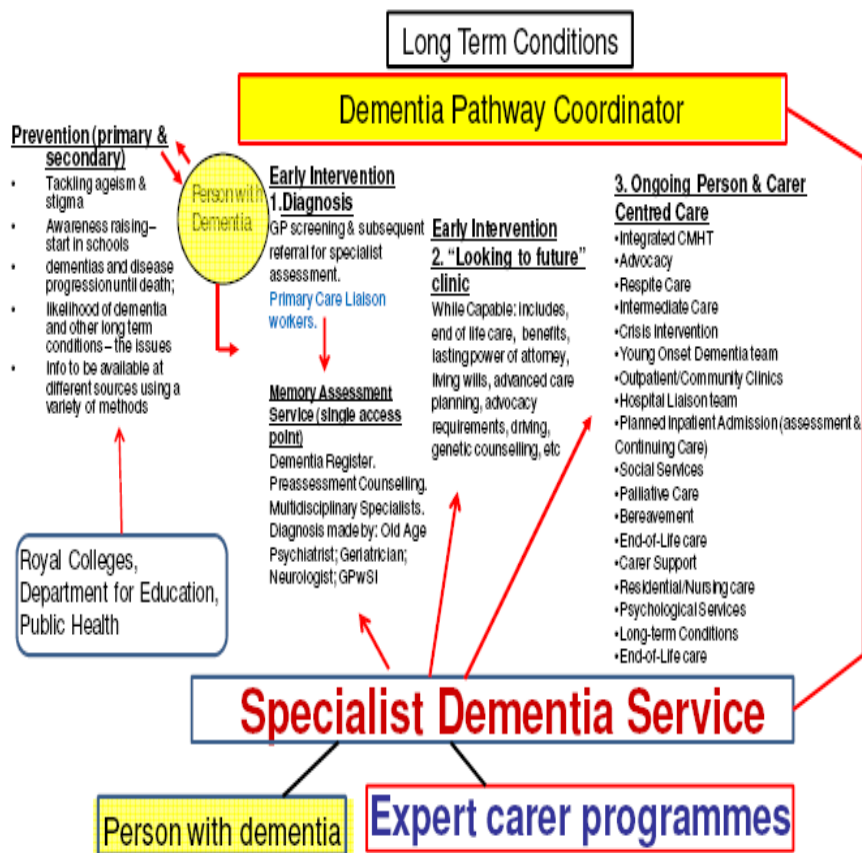
Some Standards we might expect:

1. Health and social care jointly plan and commission a service for people and their carers with Dementia which provides seamless, integrated and proactive care

2. The specified services for dementia interface with services available for all other long term conditions and those for older people
3. Interventions are available closer to home with home as the base starting point
4. The employed workforce will be competent to address physical and behavioural symptoms
5. Sources of intimate carers will be resourced
6. Each dementia service will have a Co-ordinator service which is accessed and will be available throughout the disease process
7. Existing disease registers in GP practices will be used to trigger preventative actions for defined types of dementia
8. Minimum core standards of competency for dementia care will be used to underpin all education programmes for staff working with these people

New Pathway

Features of a good care pathway



4. National Dementia Strategy

This can be consistently set alongside the currently draft national strategy, which has been focussing on :

- Improved public and professional awareness of dementia – health promotion and education
- Early diagnosis and intervention – specialist memory assessment for all new cases
 - Commissioning a single point of referral for diagnosis in each area
 - Simple referral process and rapid response

- Making the diagnosis well; breaking the diagnosis well
- Immediate and direct provision of treatment and support
- High quality care and support for people with dementia and their carers – from diagnosis to end of life care
 - Continuity of care- developing the role of dementia care advisers
 - Quality of care in acute hospitals – general skills and liaison
 - Quality of care at home – home care and mental health teams
 - Quality of care in care homes – improved training and in-reach
- Delivering the strategy

5. Stepped Care

Although neither the West Midlands document nor the draft national strategy sets out service development under this model, its approach can also be used to view and develop services; with the aim of increased community information and understanding, assisting self help; core care and support being provided at the level of primary care and community services; additional interventions when required being provided by community based secondary and specialist services, particularly age old psychiatry, working in partnership with primary care; exceptionally, residential secondary and specialist services being needed, particularly care homes and in-patient services, and very occasionally, regional investigations and treatment, such as neurology. There are different models of how memory assessment services could be provided, whether primary or secondary care based.

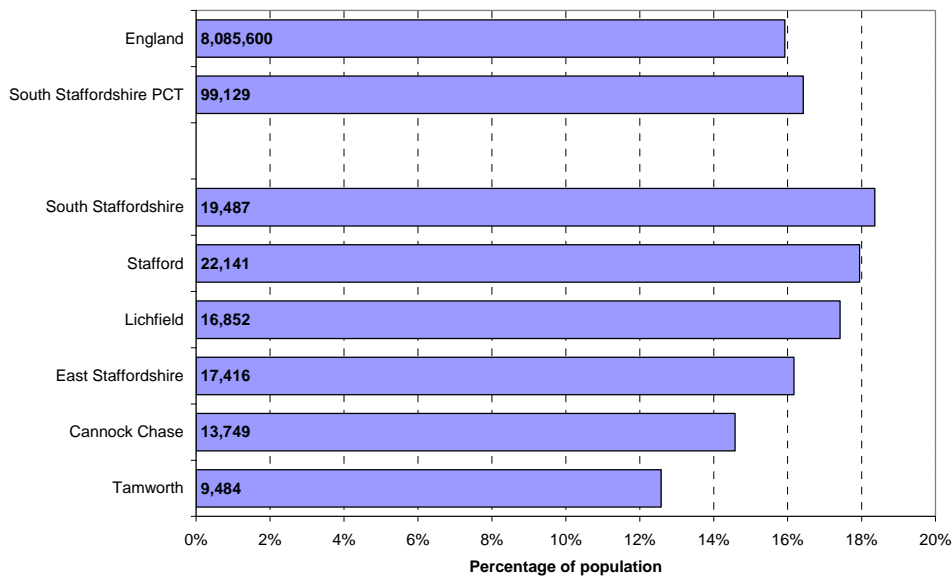
6. Demography and prevalence

The information in this section is primarily drawn from 'Older people's mental health: assessment of needs and services' – South Staffordshire PCT and Staffordshire County Council, the West Midlands Dementia Report and the consultation draft National Dementia Strategy.

Population

The PCT covers a GP registered population of 608,850 and resident population of 603,695. Whilst the PCT overall is broadly similar in age structure to England, some local authority areas have higher numbers of older people compared to the national average, i.e. South Staffordshire, Stafford and Lichfield.

Figure 1: Percentage of people aged 65 and over by local authority, 2006



Source: 2006 mid-year population estimates, National Statistics, Crown copyright

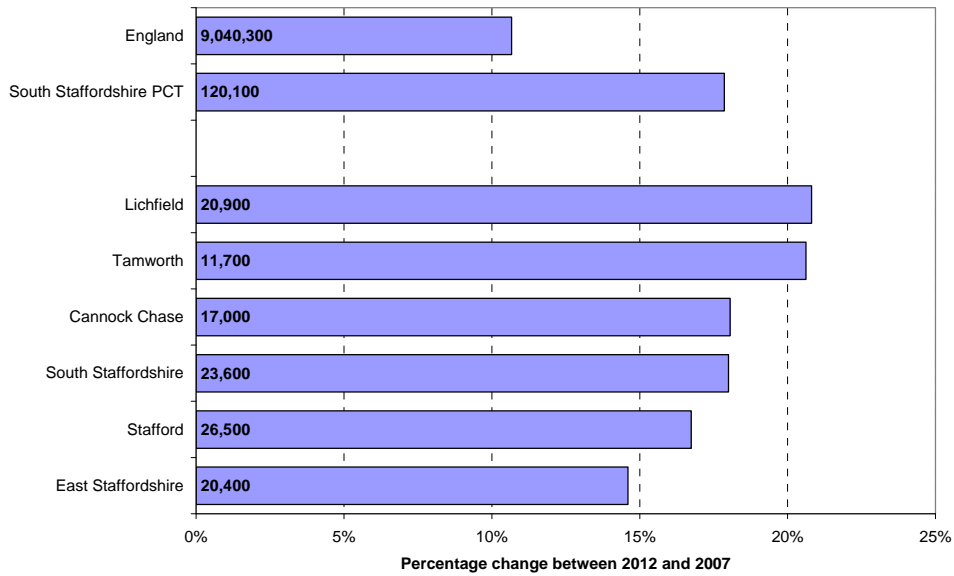
Population projections

Population projections, based on revised 2004 mid year population estimates for the PCT for the next ten years, show that South Staffordshire PCT will see:

- a small growth in the overall population (3% compared with 5% for England)
- reduction in numbers of people aged under 16 (6% decrease compared with 0.5% decline nationally)
- significant decline in people aged 16-44 (7% reduction compared with 2% decrease for England)
- a growth in the 45-64 age group (6% compared with 10% nationally)
- a significant growth in people aged 65 and over (34% compared with 22% nationally), with particular growth in the numbers of people aged 75 and over.

Over the next five years, areas such as Lichfield and Tamworth will see significant growth in numbers of older people.

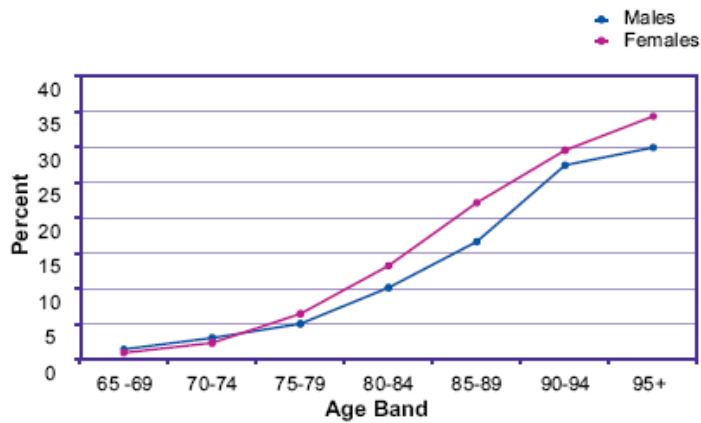
Figure 2: Percentage change between 2007 and 2012 in people aged 65 and over (number of people in 2012) by local authority



Source: 2004-based sub-national population projections 2004-2029, National Statistics, Crown copyright

Estimated number of older people with dementia for South Staffordshire PCT and future projections of need

Figure 3: Estimated population prevalence of late onset dementia by age group, UK (Expert Delphi Consensus method – studies from various years)



Source: The Expert Delphi Consensus on the prevalence of dementia, Dementia UK, Personal Social Services Research Unit (PSSRU 2007)²

A recent source of national data for the prevalence of dementia is the 2002 Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS). Prevalence for men and women by age group for dementia is shown in Table 2. Based on these age-specific prevalence rates, it is estimated that there will be just under 3,500 men and 6,200 women with dementia aged over 65 years in Staffordshire in 2017 (Table 3). The projected increase in the number of people with dementia by age group over the next 20 years is shown in Figure 44.

Table 2: Prevalence of dementia in England and Wales 2002

	Men	Women
65-69	1.4%	1.5%
70-74	3.1%	2.2%
75-79	5.6%	7.1%
80-84	10.2%	14.1%
85+	19.6%	27.5%

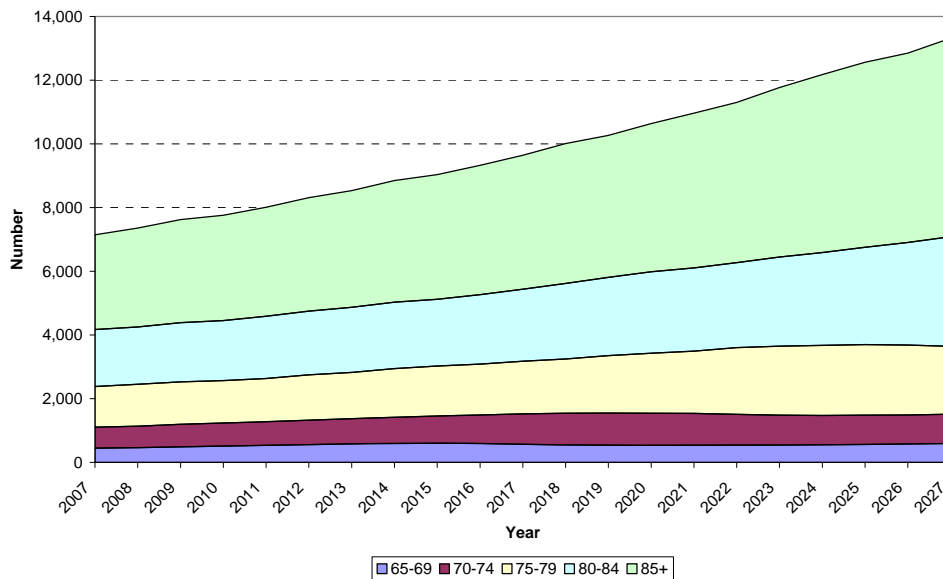
Source: Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS), February 2002, taken from Projecting Older People Population Information System, <http://www.poppi.org.uk/index.php>

Table 3: Estimated numbers of people with dementia aged 65 and over by local authority

	Men			Women		
	2007	2012	2017	2007	2012	2017
Cannock Chase	326	369	441	675	847	970
East Staffordshire	413	480	571	837	900	1,008
Lichfield	393	504	618	795	883	1,013
South Staffordshire	464	581	707	917	1,069	1,231
Stafford	548	667	804	1,136	1,276	1,419
Tamworth	213	249	308	434	490	552
South Staffordshire PCT	2,357	2,850	3,449	4,794	5,465	6,194

Source: 2004-based sub-national population projections 2004-2029, National Statistics, Crown copyright and Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS), February 2002, taken from Projecting Older People Population Information System, <http://www.poppi.org.uk/index.php>

Figure 4: Projected numbers of people with dementia aged 65 and over for South Staffordshire PCT



Source: 2004-based sub-national population projections 2004-2029, National Statistics, Crown copyright and Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS), February 2002, taken from Projecting Older People Population Information System, <http://www.poppi.org.uk/index.php>

7. Activity analysis

In Patient Activity, South Staffordshire

Most care that is provided to older people with mental health problems is by family carers, by community social and primary care services, or in a care home. It is only a very small fraction of the total who are admitted to a hospital for mental health reasons, but this is an often traumatic, prolonged episode with significant cost consequences for the NHS.

As well as those people who are admitted to hospital for specialist reasons on account of their mental health needs, there are also many people in acute and community hospitals where the dementia is not the cause for their admission but will have an impact on how they experience hospital. They will probably find it very frightening and the hospital staff will find communication and understanding their needs particularly difficult. Given that up to 70% of hospital beds are occupied by older people and up to a half of them may be people with cognitive impairment including dementia and delirium, this is a major challenge to mainstream services, reflected in people with dementia having worse outcomes in terms of length of stay, mortality and institutionalisation (Draft National Strategy).

Table 4 shows the yearly total of admissions for mental health reasons of people over 65 by South Staffordshire PBC consortia – between 225 and 280 admissions take place each year.

Table 4: Total admissions by PBC area and year

PBC	2004/05	2005/06	2006/07	Total
Cannock Chase	43	48	33	124
East Staffordshire	49	39	46	134
Seisdon Peninsula	25	14	18	57
South East Staffordshire	71	58	75	204
Stafford and Surrounds	26	74	21	121
NULL	39	46	33	118
Total	253	279	226	758

Figures 5 and 6 show age standardised non elective and elective admission rates respectively, standardised to take the age structure of the population into account. Non elective admission rates are lowest in Stafford and Surrounds PBC, and South East Staffordshire has the highest elective admission rates, both of which may reflect the nature of other health and care services.

Figure 5

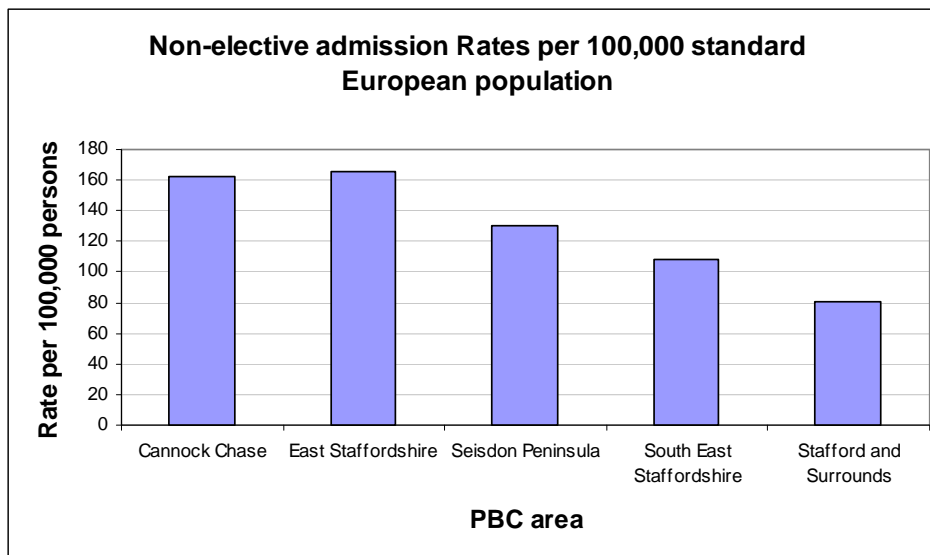
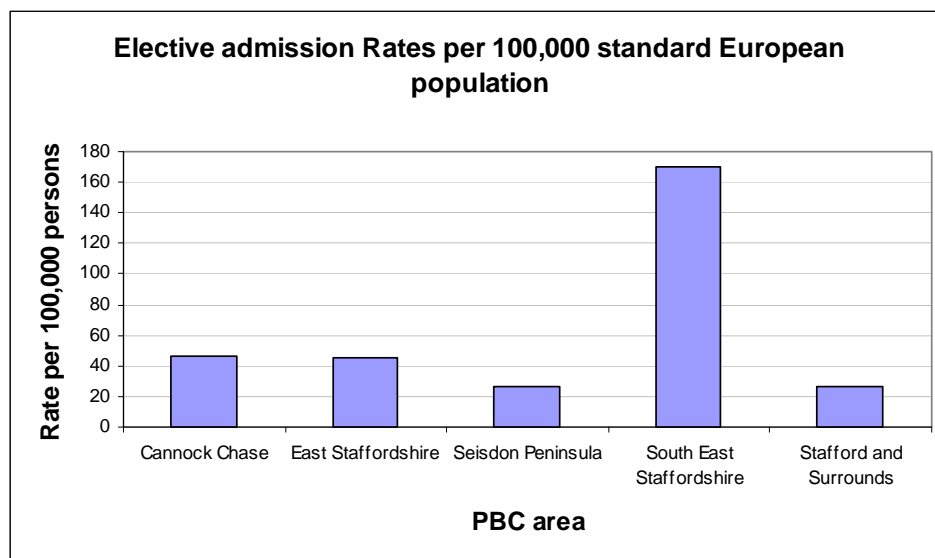


Figure 6



Ethnicity

Table 5 breaks down admissions by ethnicity – overall, 89% of patients admitted describe their ethnicity as White, compared to 94% of the population of Cannock Chase. 0.8% of admissions in Cannock Chase PBC are Asian or Asian British compared to 0.1% overall. However, 11% overall did not have any ethnicity stated, which was highest in East Staffordshire, at nearly 16% not recorded.

Table 5: Total admissions by Ethnic Group

PBC	White	Asian or Asian British	Black or Black British	Mixed	Not stated	Total
Cannock Chase	94.4%	0.8%	0.0%	0.0%	4.8%	100%
East Staffordshire	83.6%	0.0%	0.7%	0.0%	15.7%	100%
Seisdon Peninsula	93.0%	0.0%	0.0%	0.0%	7.0%	100%
South East Staffordshire	85.8%	0.0%	0.0%	0.0%	14.2%	100%
Stafford and Surrounds	91.7%	0.0%	0.0%	0.8%	7.4%	100%
NULL	90.7%	0.0%	0.0%	0.0%	9.3%	100%

Total	89.1%	0.1%	0.1%	0.1%	10.6%	100%
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NHS Trust

Most admissions for South Staffordshire PCT residents are to South Staffordshire and Shropshire NHS Foundation Trust; of the 758 admissions over those 3 years, 722 were to that Trust.

Reason for admission

The information on this is unreliable: of the 758 admissions over of people over 65 with mental health problems, over 300 admissions were poorly coded or had an invalid primary diagnosis. This makes it impossible to have a certain picture of admissions for patients with dementia. However, of those with a valid diagnosis, 'senile dementia' was second only to 'depression without section'. The average length of stay was 64 days. The overall estimated spend on in patients from 2004/05 to 2006/07 was, on average, nearly £4 million per year – just over £3.5 million on patients admitted to South Staffordshire and Shropshire Healthcare NHS Foundation Trust.

National Comparison Data - admissions by diagnosis category

Table 6 shows local and national comparative data for the percentage of admissions to any specialty for a specific psychiatric diagnosis of dementia for those aged 65 and over. These data show that:

- The proportion of admissions for dementia increases with increasing age (unlike the proportion of admissions for mood disorder (mostly depression), neurotic disorders and schizophrenia, which decrease with increasing age).
- Staffordshire has a higher proportion of admissions for dementia (although overall numbers are lower).

Figure 7 compares admissions by age:

- The total numbers admitted by age group increases steeply with age.
- Overall age specific rates for South Staffordshire males and females are mostly lower for all age groups than national comparisons, especially in the 80 and over age group.

Table 6: Percentage of Mental Health admissions with dementia as the primary diagnosis code in the 65 and over age group 2004/05. National data compared to PCT

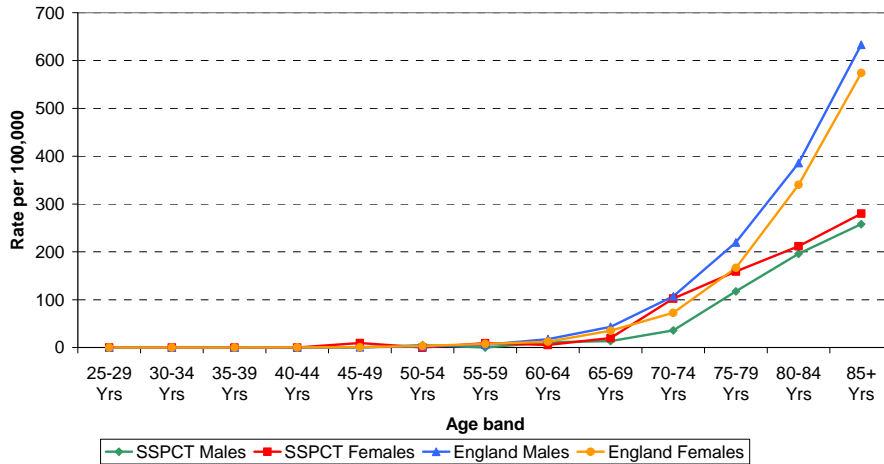
		Age Group					
		65 – 69	70 – 74	75 – 79	80 – 84	85+	65 & over
Dementia	National	13.2	26.0	38.9	51.4	61.1	40.5

	PCT	17.0	35.0	41.5	50.0	72.3	43.2
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Source: Hospital Episode Statistics 2005-06

Primary diagnosis ICD10 code F00 – F99 in the over 65 age group

Figure 7: Age specific admission rates, Dementia, 2006/07



Source: DH Hospital Episode Statistics/ONS Mid Year Population Estimates

Note: England rates displayed are for 2005/06

So in conclusion, a significant number of people with dementia in South Staffordshire arrive in hospital for assessment and treatment of that condition; once there, they stay for a long while at considerable cost to the health economy. The admission rates vary considerably between PBC consortia and this merits further consideration. South Staffordshire has a smaller proportion of its population in hospital with this condition than nationally but a higher proportion of mental health admissions are for dementia, so this lends itself to a targeted approach. Most patients are of very advanced years and they are overwhelmingly white, which poses a particular challenge to services in caring for patients from minority communities, and in caring for people with a wide spectrum of ages. Recording of ethnic origin is poor and needs improvement.

Care home admissions

Currently around 15% of admissions to older people’s care homes funded by Social Care and Health concern a person clearly identified as having a primary need associated with dementia. There is, however, reason to think this may be an underestimate, and local intelligence and national evidence indicate that the long term population of care homes contains a much greater proportion of people suffering from dementia – over 50% and on some estimates up to 80%.

8.Current pathways

Asked to describe current pathways, a local psychiatrist specialising in work with older people described them as 'a labyrinth'. Attached as Appendix 1 and 2 are case examples prepared by a local psychiatrist and a local carers' worker which identify some of the failings of the current arrangements and how these could change in order to transform the patient and carer experience. There is no consistent set of arrangements across south Staffordshire, limited memory assessment services and no reason to doubt that the national figure of only around a third of people with dementia ever being diagnosed applies here too. Without diagnosis, there is no access to any information, treatment or support for people with dementia or their carers. Professionals may be reluctant to offer a diagnosis, with an absence of support systems available to offer patients or their carers, although there are a few excellent services already in place. It is a truism that dementia symptoms are sometimes dismissed as 'just old age', leaving those involved to live with the increasing confusion and despair which dementia can lead to; without support to prepare for and deal with 'end of life', there is eventually very often a very unhappy and inadequately supported death.

9. Current funding

As there are currently not dementia specific services, it is not at all easy to identify current local expenditure in the NHS and social care for people with dementia. The services they receive are a part of the overall activity and costs of primary care, particularly GPs, practice nurses and some health visitors; social care assessment and provision such as day services and home care; residential and nursing care, including people who are funded for continuing healthcare; voluntary sector services - some specific such as from the Alzheimer's Society, others more broadly based, such as from Age Concern or the Carers Association; acute hospitals, where as stated above dementia will have a major impact on length of stay and outcomes even though it is not the reason for admission, and of course in the Healthcare Trust, where services to people with dementia are a major part of the activity of services for older people, in the community and in in-patient settings. People with dementia - and in consequence some of their carers too - are also significant users of the prescribing budgets of the local NHS.

In the time that this group has been meeting it has not been possible to disentangle the current expenditure but work to do so will continue so that the changes in activity which result from this strategy can be measured in terms of their impact on expenditure flows. This will never be straightforward; as shown above, current information about reasons for admission of older people to secondary care for mental health reasons is not reliable information; in the early stages of support and assessment, it is often not clear whether somebody does have dementia; information about the main reasons for admission to a care home will not reflect the number of people who have developed dementia while resident. So there are

always likely to be limitations to the information which can be used in monitoring expenditure and changes.

10.Savings through service development

The proposals in this strategy, as in the West Midlands report and the draft national strategy, are about establishing new services or expanding current services. This reflects both the attention now being given to an area which has been relatively neglected and the continuing growth in the numbers with the condition. This is not therefore a strategy which will overall deliver direct savings – dementia is a long term condition, without certain methods of prevention or known cures, so there are no high impact savings to be introduced.

The pathway and services are, however, predicated on the value of giving information, early intervention and continued treatment and support through high quality accessible local services. These are intended to give greater control and supported management of the condition to the person with dementia and carers involved. Additionally, there are proposals which strengthen the approach in acute hospitals and care homes. All are designed to reduce the likelihood of crisis, and to support the maintenance of current arrangements, and prevent unnecessary movement in to higher intervention and higher cost services. Experience locally and nationally indicate this is what people want and value highly when they receive it.

The draft national strategy has an Appendix entitled ‘ The clinical and health economic case for early diagnosis and intervention services in dementia’; this says that its assumptions should be treated with caution, but looks at the savings that would be achieved by reduced admissions to care homes for public expenditure and for people who privately fund themselves. It is developed from the Department of Health’s Croydon early intervention pilot and other research and states: – ‘ the analyses suggest that it would be clinically effective and cost-effective to invest in such services’.

It considers 6%, 10% and 20% reductions in care home admissions and sees an overall ‘break even’ for society with around a 10% reduction over 10 years, starting to take effect in year 4, and this reduction would also usually be accompanied by a higher quality of life. It states – ‘In the estimation of benefits, no calculation is made of the savings which might accrue from early diagnosis in terms of reduced use of acute hospital beds, by prevention of admission and the facilitation of discharge, or decreased use of community social care by the early provision of advice, treatment and support. This direct health service saving may be extensive, with the National Audit Office estimating that re-engineering systems for dementia could yield £6.5 millions of acute trust savings per year in a single area (Lincolnshire).’

Faced with the currently inexorable growth in people with dementia in South Staffordshire, this evidence strongly indicates that change has to be introduced

both for the quality of life of the people involved and also for the benefits it will bring to health and social care systems.

11. Priority developments of the new model

The West Midlands model of a 'good pathway' above makes clear just how many services are involved in the care and support of a person with dementia and their carers. All have their part to play in the three main aims of the national dementia strategy and the aspiration of a comprehensive range of services as in the good pathway must drive continuous improvement in this so far relatively neglected field. But there is a need to start with priority areas and the following are seen as priorities given the needs, services and gaps identified in South Staffordshire. They are grouped under the main aims of the draft national strategy but connected to the good pathway.

Although there is an interdependency between the various elements – so, for example, having very improved assessment services will be of relatively little use without services with which to follow up – the SIB agreed that the most urgent and highest priorities are 1. the development of memory clinics to allow for all referred need to be assessed, and 2. the establishment of dementia care co-ordinators to provide continuing points of reference and support for people with dementia and their carers. Other recommendations are also made as these are necessary developments to improve the quality of life for people with dementia and their carers and several can be made at relatively low cost.

Improved public and professional awareness of dementia

i) Primary care awareness and training programme: a tailored programme of information for primary care staff to alert them to the symptoms of dementia, local services and to sensitise them to working with people with dementia and their carers. This is being made a priority as there is evidence of very low diagnosis nationally in primary care and in local case feedback and it is the most likely location which patients and carers will come to with early concerns. Poor response may drive many people away. There may be a national programme to follow the publication of the national strategy in the autumn, in which case this will be followed but made locally sensitive.

Estimated cost 2009-10 - £10,000

ii) Public information and awareness campaign: although this will be an essential element – and is already trailed by various campaigns (e.g. 'Worried about your memory?' – DH and Alzheimers Society 2008), this will be taken forward and locally tailored in line with the national campaigns which must follow the publication of the national strategy.

Estimated cost 2009-10 - £10,000

Early diagnosis and intervention

iii) Early diagnosis memory assessment service/s of a size and capacity to meet the current and immediately identified level of need – referral through GPs, social care and from hospital, with an expectation that primary investigations will already have been completed. Incorporating pre- and post-diagnosis counselling and with access to therapy services across age, they should provide high quality information on the nature of the condition, treatment and available support. Given the physical, mental and emotional changes resulting from the condition, AHPs should be linked in to this service. An early intervention ‘looking to the future’ service should be connected to the service.

Estimated cost 2009-10 and onwards - £400k rising to £480k by 2012

This is based on information about the memory service in Shropshire; the costs excluding drugs are approximately £300k for a population of 70,000 over 65 years old; this provides for 1 Band 7 lead nurse, 4 Band 6 nurses, 0.6 associate specialist and 2.1 secretaries, with travel costs, room hire, telephones etc. The figure above extrapolates this for Staffordshire’s population over 65 years of 99,000 in 2007, rising to 120,000 in 2012. The cost does not include the cost of staff providing ‘looking to the future’ services or the costs of AHPs, but further work is needed to explore the costs of other models such as primary care based models, and whether there are any elements of current services which could be re-directed to this service.

The estimated cost does not include the increase in prescribing which is likely to result from wider early intervention.

iv) Pilot a local dementia care coordinator service. The draft national strategy uses the term ‘dementia care advisers’, the West Midlands report describes ‘dementia pathway co-ordinators’ – both have a similar purpose in assisting patients and carers to access and be appropriately treated across health and social care services, for all their needs, not just dementia. The professionals in these roles would understand the condition and the ways it develops, be aware of the local services, and act where necessary as advocate and supporter to the person with dementia and their carers throughout the life of the disease. They would be a source of information about service development needed. There are currently posts within the Alzheimer’s Society and Carers Association which undertake some similar functions and there are some professional posts, such as CPNs, Health Visitors and social workers, who will be in a position to undertake these roles. But the function and capacity required will need further development in the light of local and national evidence so at this stage it is proposed that two further posts be established with an action-research remit. These posts should be located with the early diagnosis and intervention services. If primary care and secondary care memory clinics are developed locally, then these posts could be based in each in order to further and test the local models of integrated care.

Estimated cost 2009-10 and onwards - £60,000

High quality care and support for people with dementia and their carers

Quality of care in acute hospitals

v) Pilot a clinician led dementia pathway in the Mid Staffordshire NHS FT and expanded mental health liaison team to include one specialist dementia post. Local feedback, e.g. from the Carers Association, has reinforced the problems there can be in acute and community hospitals for people with dementia and their carers, as well as for staff trying to help them, as described on page 10 above. The draft national strategy proposes a clinician taking the lead for dementia and commissioning older people's mental health liaison teams. There has already been a pilot of a member of the psychiatric liaison team working on Littleton Ward earlier in 2008 which was considered to have reduced previous delays in discharge planning and was able to undertake considerable staff training. This proposal would inform wider roll-out across the PCT. The Trust is keen to be involved in this service improvement. There is already a 0.8 Older Age focussed Liaison Nurse in the psychiatric liaison service, funded through the Healthcare Trust; it is proposed that an additional 1 fte Band 6 post be added to the team, with an evaluation programme for the changes in the hospital.

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Estimated cost £2009-10 - £40,000, may increase in the light of the pilot.

Quality of care at home

vi) Extend the function of intermediate care and reablement services to include people with dementia. Currently people with dementia are often excluded from intermediate care services, particularly if their behaviour challenges staff. However, appropriately skilled and supported staff and, where appropriate, residential accommodation, can provide invaluable opportunity for comprehensive assessment and skills development for the person with dementia and carers. This can enhance the potential for longer term continued life at home. Intermediate care services would require support to be available from community mental health teams. This proposal will require more detailed planning across health and social care to determine what development and funding is required, for example in accommodating people with physical frailty and people with dementia. As a minimum, it is proposed that two additional CPNs are established to work with intermediate care and reablement services.

Estimated cost 2009-10 and onwards subject to evaluation - £90,000

vii) Introduce an enhanced training programme for home care staff who are likely to be working with people with severe dementia or complex needs. The Social Care and Health provider home care service will undertake assessment and care planning in the first six weeks of intervention. They will need to be appropriately

skilled and networked to undertake this role for people with – or who may have – dementia. For longer term care and support, providers need to be in place who are able to work with people with such needs and this will need to be taken account of in tendering processes and service specifications in Social Care and Health. With personal budgets, people who are using these to choose services will need to know that there are suitable providers available locally.

Estimated cost 2009-10 (to Social Care and Health) - £10,000

viii) Develop respite short breaks which are capable of urgent and planned respite for people with dementia and their carers. Social Care and Health are planning for the use of the small number of retained homes for older people that will be retained by Staffordshire County Council. There will be three homes which will specialise in providing care for older people with mental health needs and an element of that will be for respite care. Additionally, a small amount of new funding for carers services is being made available by the Department of Health and it should be proposed that some of that is made available to carers of people with dementia, with the aim of providing urgent or planned respite in very flexible ways to suit individual need.

Estimated costs (to Social Care and Health) 2009-10 and onwards - £50,000

This is an estimate of funding which can be provided from the additional Grant; there will also be loss of residential care income to the Local Authority as it changes usage from long term care to respite.

ix) Pilot expansion of the current mental health support line to include older people with dementia and their carers. There have been several comments, particularly from carers, about the concerns at not having anyone to seek advice or support from outside office hours. Given there is currently a well regarded service locally for adult mental health, the potential to pilot an expanded service should be tested with them.

Estimated cost 2009-10 and onwards subject to pilot - £10,000

x) Review the protocols for the prescribing, monitoring and review of anti-psychotic medication for people with dementia

There has been national concern about use and abuse of this medication. NICE has published guidelines which have been implemented in part in South Staffordshire, but have been found to be very labour intensive to implement. It is proposed that clinicians and prescribing advisors should review and develop a local position on this.

Estimated cost 2009-10 – the review can be managed within current budgets. The outcomes of the review will need consideration.

Quality of care in care homes

xi) Expand the current care home inreach and support service to cover the west of South Staffordshire as well as the east.

Care homes are often caring for the people with the most advanced dementia and complex needs. Skilled support to them has been found to assist in the care and management of the conditions and to prevent escalation of the services required. Currently, historical legacies mean only half of the PCT receive this service, and this 'postcode' inequity should be rectified.

Estimated cost 2009-10 and onwards - £40,000

xii) Develop the functions of the retained specialist Social Care and Health care homes

The County Council is currently planning for the use of three care homes in South Staffordshire which will provide a specialist resource for older people with mental health needs. These will be able to take people with more complex needs and behaviour which challenges services, and will be able to provide respite services as described above. The staffing establishment for the day time has been planned incorporating £300,000 which has been allocated by the PCT for similar purposes and it is proposed that this funding remains allocated for that purpose. Night time care is not yet adequately funded for that purpose and Social Care and Health will provide the funding for that purpose, in addition to its core funding for the whole service.

Estimated cost 2009-10 and onwards – PCT £300,000 already allocated; SC&H to be identified.

Others

xiii) Enhance end of life care for people with dementia

There is currently a post located in the Healthcare Trust, funded by the PCT, which is reviewing end of life services for people with dementia; the outcomes of this work and the tie in with the Service Board for end of life services will no doubt lead to improvements in this critical area, but their cost is not yet clear. This will need to be joined up with the development of an 'end of life' service.

xiv) Ensure services are appropriate for groups who are often excluded.

As services are developed, equality issues should be at the forefront. People with dementia who have sensory impairment, or whose first language is not English, or who are from ethnic groups often subject to racism, are likely to be doubly disadvantaged. As services are reviewed and developed, there should be equality impact assessments and suitable engagement and consultation, recruitment and

training. This should be managed within the budgets of organisations for such approaches, but will be a factor in the specification and tendering for services.

Malcolm Dillon

Interim County Commissioner

Staffordshire Joint Commissioning Unit

30th August 2008