AGENDA ITEM 7

Dementia Services: early diagnosis and access to services

Report of the Health Scrutiny Committee

March 2010

Foreword and Acknowledgements

Panel Members

Councillor Tom McGee

Councillor Walter Brett

Councillor Christine Corris

Councillor Chris Gordon

Councillor Sylvia Humphries

Councillor Bryan Leck

Councillor Hazel Lees

Councillor June Somekh

Councillor Craig Wright

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1. Executive Summary

1.1 At its meeting on the 15th September 2009, the Health Scrutiny Committee agreed to carry out a scrutiny review relating to early diagnosis and access to support for people with dementia in Stockport.

1.2 Improving dementia services is increasingly becoming a key national and local priority. Research shows there is a vast amount that can be done to help improve and maintain the quality of life experienced by people living with the condition.

1.3 Early intervention and positive input from health and social care services and from the third sector can help to ensure people with dementia continue to live a fulfilling life. People have more timely access to treatments and support; and both patients and carers have an opportunity to acquire an understanding of the condition, empowering them to make choices regarding their future care.

1.4 Furthermore early access to support can help to prevent future crisis situations, which often result in lengthy and cost intensive hospital stays and / or residential care.

1.5 Early diagnosis and support for people with dementia has, however, been identified as an area for improvement. Nationally, currently only about 1/3 of people with dementia receive a formal diagnosis or have contact with specialist services at any time during their illness.[1]

1.6 In addition many of those who do receive a diagnosis are brought to the attention of healthcare professionals at a point of crisis when they are already suffering from a moderate or severe dementia. For the majority of these people their condition is too advanced to benefit from the support available and in most cases they are subject to lengthy hospital stays and residential care.

1.7 In recent months significant efforts have been made, at both national and local level, to raise the profile of dementia and drive forward improvements to the support and services available to people living with the condition. The Department of Health's first ever National Strategy for Dementia was published in February 2009, followed by an Implementation Plan in July 2009; and a local Dementia Strategy specifically for Stockport is currently undergoing consultation and will be ready by May. (attached as an appendix)

1.8 Development is, however, at an early stage and a report published by the National Audit Office in January 2010 claimed that development

[1] Department of Health (February 2009) The National Dementia Strategy, p17

across the country is still “patchy” and not given “the priority and urgency” it deserves.[2]

1.9 By choosing to carry out a piece of in-depth scrutiny work relating to early diagnosis and access to support for people dementia in Stockport, the Health Scrutiny Committee felt it has a timely opportunity to help raise the profile of dementia and contribute to current developments at a local level around this important issue.

1.10 For the purpose of the review, the Committee agreed to focus on early identification and access to support for people with dementia over the age of 65. However the Committee recognises that young onset dementia is also a key priority and that younger people with dementia have different support needs from older people diagnosed with the condition. The Committee welcomes and supports the measures contained in the Stockport Dementia Strategy to review and develop care provision for this group of people.

1.11 As a result of this Scrutiny Review the Committee has identified fourteen recommendations, covering a range of practical and strategic issues including:- raising public awareness of dementia and dementia support; the provision of support across the borough for people living with dementia; and the role of GPs and staff in general hospitals in improving diagnosis rates and signposting to support. The Scrutiny Committee’s fourteen recommendations are set out below:

Recommendation 1
The Committee recommends that initiatives are piloted to promote positive messages regarding the support available during, and after, diagnosis of dementia. In particular, the Committee recommends that NHS Stockport commissions a mobile “memory services” vehicle in public areas such as shopping centres, designed to raise public awareness of memory conditions and the wide range of support available to people with dementia and their carers. The Committee welcomes this provision at the earliest opportunity but definitely during the 2011/12 financial year.

Recommendation 2
The Committee recommends that one GP from each of the four Practice Based Commissioning Areas is identified as a “Dementia Champion,” with responsibility for: - raising GPs’ awareness of dementia; raising awareness of the role of GPs’ in identifying symptoms of dementia and signposting patients and carers to support; promoting dementia training for GPs; and disseminating up-to-date information regarding dementia and dementia support. The Committee recommends that NHS Stockport implement this recommendation as soon as is possible.

[2] National Audit Office (January 2010) Improving Dementia Services in England: An Interim Report, pp6-10

Recommendation 3
The Scrutiny Committee recommends that GP training should be complemented by public information campaigns which encourage people to access their GP about concerns regarding their memory.

Recommendation 4
The Committee recommends that:
i. NHS Stockport carry out a thorough analysis of diagnosis rates by individual ward area in order to identify areas with lower than expected diagnosis rates for dementia (allowing for natural variations associated with the demographic profile of individual areas);
ii. Localised targeted action to improve diagnosis rates is based on the above analysis.

The Committee welcomes this work during the 2010/11 municipal year.

Recommendation 5
The Committee recommends that:
i. Stockport NHS and Stockport Council (Joint Commissioning), in conjunction with the voluntary and community sector, carry out a gap analysis to identify demand for support across the borough and ensure provision is mapped to meet local demand.
ii. Stockport NHS consult with the voluntary and community sector on an annual basis in order to carry out up-to-date audits of services and help ensure provision of dementia services continue to meet demand.

Recommendation 6
The Committee recommends that:
i. Further voluntary and community provision is encouraged and proactively supported by the Council as a low cost option to complement existing services and fill any gaps in provision (both in terms of location and type of service provided). In particular, the Committee recommends that the luncheon club operated in conjunction with Bramhall United Reform Church is considered as an example of good practice to be encouraged in other parts of the borough.
ii. The specific needs of BME groups are considered and support is tailored to meet their needs.

Recommendation 7
The Committee recommends that joint working between NHS and voluntary service providers is encouraged in order to provide a more integrated and comprehensive service. In particular, the Committee welcomes the proposed community memory services “hubs” and recommends that they are introduced and monitored during the 2010/11 municipal year, with a view to further developing the service across the borough.

Recommendation 8
The Committee recommends that arrangement for internal monitoring, by Stockport NHS Foundation Trust Board, of progress in relation to the implementation of the Trust's dementia action plan is built into the plan. This will help to raise awareness and support for the plan at the highest strategic level.

Recommendation 9
The Committee acknowledges that a specialist mental health liaison service, in line with national good practice, would derive substantial benefits at a relatively low cost. The Committee recommends that such specialist mental health liaison service is commissioned by NHS Stockport during the 2011/12 financial year.

Recommendation 10
The Committee has found that evidence suggests there are benefits to be had from prompt hospital assessment and streamlined pathways through hospital for people with dementia. To this end the Committee recommends that:

i. Measures are implemented to speed up the time taken to carry out an effective hospital assessment of patients who are in an acute hospital;
ii. The pathway through hospital for patients with dementia is streamlined, and unnecessary transfers during hospital stay avoided.

The Committee welcomes this action at the earliest opportunity.

Recommendation 11
The Committee recommends that:

i. All relevant stakeholders and dementia service providers sign up to the local dementia strategy and implement the appropriate actions in their organisations;
ii. The Stockport Older People's Working Group (mental health) takes a proactive role in monitoring the implementation of the Strategy;
iii. An annual report on performance in relation to the actions contained in the local dementia strategy is presented to the Health and Wellbeing Partnership Board.

Recommendation 12
The Committee recommends that membership of the Stockport Older People's Working Group (mental health) is refreshed to include representation from Stockport NHS Foundation Trust, in addition to all other relevant stakeholders from the PCT, Pennine Care, Stockport Council and voluntary and community sector.

Recommendation 13
The Committee recommends that:

i. A local set of targets and performance indicators focusing on specific priorities for improvement in relation to dementia services,

is developed and agreed by the Health and Wellbeing Partnership Board;

ii. All NHS and voluntary service providers are encouraged to sign up to the targets; and performance is reported to the Health and Wellbeing Partnership Board.

iii. The targets are reviewed on an annual basis.

Recommendation 14

The Committee recommends that a further meeting is held in twelve months time, with all stakeholders, to monitor progress towards implementing the recommendations contained in this review and to evaluate early outcomes.

2. Terms of Reference

2.1 The Committee identified the following key aim and objectives for the scrutiny review:

2.2 Aim:

"To consider, from a local perspective, current provision and future plans to help increase early diagnosis of dementia and ensure all people with dementia have early access to appropriate support, care and treatment."

2.3 Objectives:

a) To consider information relating to early diagnosis rates for people with dementia in Stockport;
b) To evaluate current processes / channels for diagnosing dementia and identify any areas for improvement;
c) To carry out an audit of care and support services available in Stockport for people diagnosed with dementia (including support provided by voluntary and community sector organisations, NHS organisations and the Council) and identify any gaps in provision;
d) To evaluate patients' experiences of accessing services and the effectiveness of 'signposting' to services;
e) To consider current and future plans for improving dementia services, with particular reference to early diagnosis and access to care for people with dementia;
f) To identify any examples of good practice in other areas, relating to early diagnosis and access to care for people with dementia, and consider whether any learning can be applied in Stockport;
g) Identify conclusions and recommendations

3. Methodology

3.1 The Committee held six meetings in relation to the review's objectives. Details of these meetings are set out in the table overleaf:

Date of meeting	Purpose / objectives of meeting
22nd October 2009	• To set the scene for the review and help the Committee identify aims and objectives
17th November 2009	To discuss: • Support services for people with dementia in Stockport, including: ➢ Provision of services across the borough; ➢ Gaps in service provision; ➢ Take-up rates for services; ➢ Information/systems to signpost people with dementia to appropriate services across the NHS and voluntary and community sector (objectives c, d) • Current and future plans for integrated diagnostic / treatment pathways in Stockport (objectives b, e, f)
15th December 2009	To discuss: • Early diagnosis of dementia and access to support services from a GP's perspective, including: ➢ The current role of GPs in relation to the diagnosis of dementia and provision of support; ➢ Arrangements for integrated working with mental health and voluntary organisations; ➢ Training and support to help GPs identify signs of dementia, make effective referrals for diagnosis and deal with patients' emotional needs; ➢ The role of GPs in delivering an integrated model of diagnostic and treatment pathways (objectives b, d, e) • The demographic profile of people living with dementia in Stockport (objective a)
20th January 2010	To discuss: • Early diagnosis of dementia and access to support services from the perspective of general hospital staff (objectives b, c, d, e, f)
2nd February 2010	To identify conclusions and recommendations (objectives f, g)
16th March 2010	To approve the draft report

3.2 During the course of these meetings the Committee met with representatives from the Primary Care Trust, Pennine Care, Stockport NHS Foundation Trust, the Alzheimer's Society, Age Concern, a local GP and a carer. In addition the Committee considered the findings of consultation with service users carried out by the PCT and the Alzheimer's Society.

4. Background information

4.1 Dementia and its implications

4.1.1 The National Dementia Strategy states: "dementias are a devastating set of illnesses that have profound negative effects on all those affected, be they people with dementia or their carers."[3]

4.1.2 The term "dementia" is used generically to describe a variety of illnesses in which there is a progressive decline in memory, reasoning and communication skills and the skills needed to carry out daily activities. Alongside this decline, people with dementia may also experience behavioural and psychological symptoms such as depression, psychosis and aggression.

4.1.3 The main types of dementia are Alzheimer's Disease, vascular dementia and a mixture of the two ("mixed dementia"). The causes of these illnesses are not well understood but they all result in structural and chemical change to the brain and are eventually terminal. Dementia is more common with age; about 6 in 100 people over the age of 65 develop dementia, increasing to about 20 in 100 of those over the age of 85.[4] Furthermore people with learning difficulties have an increased risk of developing the condition.[5]

4.1.4 In addition to the devastating effects on the patient, dementia places a heavy pressure on carers. People with dementia can live with the condition for 7-12 years, during which time they will experience a progressive decline and increasingly rely on their carers for day to day tasks. Secondary symptoms such as depression, psychosis and aggression can further complicate care; and in many cases family carers of people with dementia are old themselves and experience high levels of depression, physical illness and a diminished quality of life.[6]

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[3] Department of Health (February 2009) The National Dementia Strategy, p7
[4] http://www.cks.nhs.uk/patient_information_leaflet/dementia
[5] Department of Health (February 2009) The National Dementia Strategy, p16
[6] Support for carers is a key priority at national and local level, however the Committee agreed that the issue is beyond the scope of this scrutiny review

4.2 Prevalence and cost of dementia

4.2.1 Recent research shows there is currently an estimated 700,000 people in the UK with dementia, costing the UK economy £17 billion per year.[7] Meanwhile it is estimated that approximately 3,520 people in Stockport are affected by the disease, costing the local economy around £76.6 million annually. [8]

4.2.2 The cost of dementia increases with the severity of the condition. Estimates show that people with mild dementia living in the community will on average cost £16,689 per year; people with moderate dementia cost £25,877, whilst people with severe dementia cost £37,473. The vast majority of this cost is bourn by the informal care sector with a total of £48.3 million being spent in 2008; meanwhile £8.6 million was spent by the NHS and £19.6 million by Social Services.[9]

4.2.3 National projections estimate that the number of people with dementia will double to 1.4million people over the next 30 years due to the aging profile of the population, with costs trebling to at least £50 billion a year.[10]

4.2.4 Given the aging profile of Stockport's population, the number of people with dementia living in the borough is also expected to rise significantly in the coming years. Assuming that prevalence rates remain the same, if local population changes are as expected then by 2015 there is likely to be an additional 400 people aged 65 and over with the condition and by 2025 there is likely to be an additional 1,200 people.[11] The table below shows the projected financial implications:

Year	Cost to each sector			
	NHS	Social Services	Informal Care	Total
2008	£8.6m	£19.6m	£48.3m	£76.6m
2015	£9.5m	£21.7m	£53.5m	£84.7m
2025	£11.6m	£26.5m	£66.2m	£103.2m

[7] Department of Health (February 2009) The National Dementia Strategy, p16
[8] NHS Stockport (December 2009) Setting the Context:key themes from the JSNA, p15
[9] London School of Economics and the Institute of Psychiatry at King's College London (2007) Dementia UK: A report into the prevalence and cost of dementia, Summary of Key Findings, p9
[10] Department of Health (February 2009) The National Dementia Strategy, p16

[11] Stockport Dementia Strategy (draft version, February 2010) p6

4.3 The national context – the National Dementia Strategy and Implementation Plan

4.3.1 Over the past twelve months the Department of Health has engaged in a variety of measures to raise the profile of dementia and drive forward improvements to the support and services available to people with dementia.

4.3.2 The Department of Health's National Strategy for Dementia was published in February 2009. The Strategy is a landmark document; it sets out 17 objectives for improvement across three key areas: (1) increased awareness of dementia; (2) earlier diagnosis and intervention; and (3) higher quality care.

4.3.3 Furthermore the strategy designates 7 "priority" objectives as essential foundations to progress. These include:

i. Good quality early diagnosis and intervention for all;
ii. Improved community personal support services;
iii. Implementing the Carers' Strategy;
iv. Improved quality of care for people with dementia in general hospitals;
v. Living well with dementia in care homes;
vi. An informed and effective workforce for people with dementia;
vii. A joint commissioning strategy for dementia.

In addition local NHS trusts together with local authorities and other stakeholders are encouraged to identify further local priorities, in order to address the specific needs of their area.

4.3.4 The publication of the National Strategy was followed by the launch of a National Implementation Plan in July 2009, intended to support and facilitate the delivery of the Strategy.

4.3.5 The Implementation Plan includes a structured programme of initiatives in relation to each priority objective, with measures to evaluate and report progress; and a proposed timetable for implementation. In addition it sets out the governance arrangements to secure and monitor delivery of the Strategy, including national and regional support for implementation.

4.3.6 The Plan identifies local agencies as the forum for planning and delivering improvements to dementia services. Local NHS trusts, working in partnership with local authorities and key stakeholders are given overall responsibility for planning and delivering local approaches to reform. The Department included an additional £60 million for 2009-10 and £90 million for 2010-11 in the revenue allocations for the 152 local primary care trusts, to support local implementation of the Strategy.

4.3.7 Under the Plan, Central Government assumes responsibility for providing support in an enabling role, through the establishment of Core National and Regional Teams.

4.3.8 The Plan sets out the following support structures:

- Department of Health Core National Team – to provide support where national action is required for issues with a high profile, to avoid duplication, promote consistency and facilitate regional action.

- Department of Health Regional Teams – to provide support to engage and empower local agencies as leaders in change initiatives and facilitate the development of regional coalitions to lead on multi-area improvement packages.

4.3.9 The regional teams are currently working with local NHS trusts and key stakeholders to complete baseline reviews of each locality's progress in relation to the objectives contained in the Strategy. The regional teams aim to ensure an action plan is in place for each locality by March 2010, which key partners have co-produced and co-own.

4.3.10 In Stockport, the PCT and staff from health and social care services and third sector organisations like Age Concern, Signpost for Carers and the Alzheimer's Society, have engaged in an extensive review of local services for people with Dementia. This review has been used to inform the development of a local strategy for improving dementia services.

4.3.11 Based on this review the local strategy identifies nine priorities for improvement in Stockport:

i. Better understanding of dementia;
ii. Raising awareness
iii. Early diagnosis
iv. Living well in the community
v. Carers' support;
vi. Social groups;
vii. Quality care in hospital;
viii. Quality in care homes;
ix. Staff skills and effectiveness of staff training.

The Strategy lists key actions designed to help achieve the above priorities. The Strategy is currently in draft form and was circulated to stakeholders for consultation during February 2010. (Further details regarding the priorities and actions contained in the local Strategy are set out in section 5.5 of this report)

4.3.12 This Scrutiny review provides an opportunity to contribute to, and reinforce, the priorities set out in the Strategy.

5. Scrutiny Review of Dementia Services in Stockport – Key findings and recommendations

5.1 Diagnosis rates for dementia

5.1.1 A national study carried out by Kings College London in 2007, on behalf of the Alzheimer's Society, concluded that dementia is under-diagnosed and the actual number of people with the condition is much higher than PCT data for confirmed diagnoses of dementia indicates. [12]

5.1.2 The study estimated how many people are currently living with dementia by evaluating population prevalence of the condition. It found that nationally one in 14 people over the age of 65 has a form of dementia, rising to one in six over the age of 80.

5.1.3 Local PCT data indicates that 1500 people in Stockport have a confirmed diagnosis of dementia. However the Kings College prevalence calculations for Stockport suggest that the actual number of people with dementia living in the borough in 2008 was closer to 3443.[13] This indicates a 43.6% diagnosis rate which is comparable to national performance.

5.1.4 By applying the prevalence data to census data, the study also estimated the probable demographic profile of people with dementia. Analysis of the Stockport data suggests:

- The vast majority of people with dementia living in Stockport are over the age of 74, with the largest proportion falling into the 85+ age group;
- There are over twice as many female dementia sufferers living in Stockport compared to the number of male sufferers;
- The majority of people with dementia in Stockport live in the Bramhall and Cheadle area where there are higher concentrations of older people, followed by Stepping Hill and Victoria;
- The majority of people with dementia living in Stockport have mild or moderate dementia, with approximately 12.5% of the total number experiencing a severe form of the condition.[14]

[12] London School of Economics and the Institute of Psychiatry at King's College London (2007) Dementia UK: A report into the prevalence and cost of dementia, Summary of Key Findings, pp4-5

[13] Stockport Dementia Strategy (draft version, February 2010) p4

[14] NHS Stockport Joint Strategic Needs Assessment

5.1.5 The Committee was informed that the demography reflected above differs from the demographic profile of the 1500 people on the PCT's list with a registered diagnosis of dementia:

- PCT data indicates that the majority of patients with a registered diagnosis of dementia have a moderate or severe form of the condition. The Committee felt that this suggests underperformance in diagnosing dementia in its mild and early forms and reinforces concerns that by the time many patients are diagnosed, their condition is too advanced for them to fully benefit from the support and early intervention available.

- In addition the PCT's data does not correspond with the demography of the borough; for example diagnosis rates are not higher in areas with higher concentrations of older people as expected. The Committee felt this further suggests a lack of consistency within primary care in diagnosing the condition.

5.2 Channels for diagnosing dementia

5.2.1 Self referrals

5.2.2 During the course of the review the Committee was informed that self referral for screening is crucial to early diagnosis. It was reported that early signs of dementia are not obviously visible, which makes it difficult for GPs and other healthcare professionals to identify during short consultations.

5.2.3 However, although the number of referrals for diagnostic tests has increased, the number of people accessing screening services at an early stage remains low. Recent research quoted in the National Dementia Strategy indicates that on average people currently wait up to three years before reporting symptoms of dementia to their GP or other healthcare professional. [15]

5.2.4 The Committee was informed of a range of factors which contribute to low self referral rates:

- The negative stigma associated with dementia - dementia is generally perceived as a degenerative condition with bleak future prospects and limited opportunity for treatment, thus creating a culture of denial and deterring many people from seeking a diagnosis.
- Dementia is treated as a taboo subject - the National Dementia Strategy, for example, reports that 50% of the public believe there is a social stigma attached to the condition.[16] Prevailing reluctance to

[15] Department of Health (February 2009) The National Dementia Strategy, p26
[16] Department of Health (February 2009) The National Dementia Strategy,p27

engage in conversation about dementia fosters misconceptions about the condition and reinforces the culture of denial.

- The perception that memory conditions are simply an inevitable product of the "aging process" – this popular belief deters many people from accessing help and fuels the view that their problems are 'not worth raising with health professionals.'
- Uncertainty regarding who to access for advice about memory problems – recent consultation carried out by Stockport PCT revealed that many people with dementia and carers are unsure who to turn to for help and unclear about the appropriateness of seeking advice from their GP.
- Furthermore the PCT's consultation found that there is not always a clear definition of dementia in other languages and cultures, especially in some BME communities.

5.2.5 The Committee felt that there is a need for public awareness raising campaigns to:

- Publicise the symptoms of dementia in order to help people monitor their own mental health and be alert to any early warning signs;
- Ensure people are aware of the sources they can approach with any concerns about their memory;
- Promote the support services available and ensure people know how to access support at all stages of the condition;
- Help to defuse the negative stigma associated with the condition by promoting the positive prospects for life after diagnosis.
- Raise awareness of dementia in BME communities

5.2.6 The Committee received details of a mobile "memory services" roadshow organised by Manchester NHS in conjunction with the Alzheimer's Society. The roadshow, which has been used at Manchester Arndale Shopping Centre, aims to help remove some of the stigma attached to dementia by providing information about memory conditions and the support available, in a non-intimidating and easily accessible public forum.

5.2.7 The Committee welcomed the roadshow as a means of raising awareness of dementia and dementia support to sections of the public who would be reluctant to access specialist services for information and advice. The Committee felt that people are more likely to access screening at an early stage if they recognise that services are available in the aftermath of diagnosis to provide support and facilitate a good quality of life for longer.

5.2.8 It was noted that an information bus was commissioned by NHS Stockport for National Dementia Awareness Week in 2009. The Committee felt that this type of service should be deployed in public areas in Stockport on a regular basis.

Recommendation 1
The Committee recommends that initiatives are piloted to promote positive messages regarding the support available during, and after, diagnosis of dementia. In particular, the Committee recommends that NHS Stockport commissions a mobile "memory services" vehicle in public areas such as shopping centres, designed to raise public awareness of memory conditions and the wide range of support available to people with dementia and their carers. The Committee welcomes this provision at the earliest opportunity but definitely during the 2011/12 financial year.

5.2.9 The role of GPs

5.2.10 National Institute for Health and Clinical Excellence (NICE) Guidance identifies GPs as integral to the development of a high quality system for the early identification and referral of people with a possible diagnosis of dementia.[17]

5.2.11 Primary care is often the first point of medical contact for people with suspected dementia. Many people with suspected dementia feel more comfortable initially approaching their GP rather than seeking specialist advice and some people may be accessing GP services for conditions unrelated to dementia. Consequently the Committee felt that GPs have an essential role in identifying symptoms of the condition and making appropriate referrals for diagnosis.

5.2.12 Furthermore the Committee felt that a GP's role in identifying early symptoms of dementia places them in a crucial position for tending to the emotional needs of patients and carers in the initial stages of diagnosis. Members felt GPs have an essential role in understanding the needs of dementia patients at this critical point and signposting patients and their carers to appropriate support and advice at an early stage.

5.2.13 Consequently the Committee felt that GPs have an essential responsibility to ensure their personal knowledge of dementia and available support services is up-to-date, in order to help ensure patients receive the best quality of care from the outset.

5.2.14 The Committee was informed that Pennine Care and NHS Stockport do deliver a dementia training programme for GPs, which aims to raise awareness of the condition and the support available. It was reported, however, that engaging GPs in such training is an on-going challenge;

[17] NICE, "Commissioning a memory assessment service for the early identifiaction and care of people with dementia" http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentservice/commissioningamemoryassessmentservice.jsp

and there is concern that there are gaps in many GPs' knowledge around dementia.

5.2.15 The Committee was concerned that GPs' general lack of knowledge around dementia means symptoms are not always recognised at an early stage, thereby delaying diagnosis and patients' access to treatment and support.

5.2.16 Furthermore NHS Stockport's consultation with people with dementia and their carers revealed mixed experiences of GPs. Some patients expressed satisfaction with the support their GP provided and the on-going support they received. However others complained about the "dismissive" attitude of their GP – "just saying it was ageing;" the length of time taken to get a diagnosis and the lack of follow-up support and signposting to services.

5.2.17 In addition ward statistics collected by the Alzheimer's Society suggests that there are marked variations in diagnosis rates of different GPs practices, even after natural variations associated with the demographic profile of individual areas are taken into account.

5.2.18 The Committee heard evidence from a local GP regarding the role of GPs in helping to diagnose dementia. He agreed that helping to diagnose dementia and signposting patients to support services should be a key priority. However he reported that the structure of primary care places constraints on the work of GPs. He explained that GPs are allocated ten minutes per consultation which requires a patient lead approach where the GP is forced to focus solely on the presenting symptoms and related health issues. The strict timescale prevents opportunistic screening for conditions such as dementia; and makes it difficult for GPs to identify early signs of the disease.

5.2.19 Furthermore he explained that as GPs do not usually see patients on a regular basis, it is difficult for them to identify patients with early symptoms of dementia. Particularly as in the early stages of the condition the symptoms are often not immediately obvious and would not be visible in a single ten minute appointment.

5.2.20 It was agreed, however, that GPs have an important role in responding to patients who raise concerns about their memory; by making timely referrals and signposting patients to support services. It was agreed that engaging GPs in dementia training is essential, in order to support this reactive role.

Recommendation 2
The Committee recommends that one GP from each of the four Practice Based Commissioning Areas is identified as a "Dementia Champion," with responsibility for: - raising GPs' awareness of dementia; raising awareness of the role of GPs' in identifying symptoms of dementia and signposting patients and carers to support;

promoting dementia training for GPs; and disseminating up-to-date information regarding dementia and dementia support. The Committee recommends that NHS Stockport implement this recommendation as soon as is possible.

Recommendation 3
The Scrutiny Committee recommends that GP training should be complemented by public information campaigns which encourage people to access their GP about concerns regarding their memory.

Recommendation 4
The Committee recommends that:

i. NHS Stockport carry out a thorough analysis of diagnosis rates by individual ward area in order to identify areas with lower than expected diagnosis rates for dementia (allowing for natural variations associated with the demographic profile of individual areas);
ii. Localised targeted action to improve diagnosis rates is based on the above analysis.

The Committee welcomes this work during the 2010/11 municipal year.

5.3 Support services for people with dementia

5.3.1 Services provided by the NHS

5.3.2 The Committee was informed that specialist support services for people diagnosed with Alzheimer's and other types of dementia have very limited capacity. There is a small specialist Mental Health Service, focussing on mental health issues for older people, comprising of three nurses, an occupational therapist and part time physiotherapist. The team's limited capacity means resources have to be targeted at patients with extremely complex needs and are reserved for critical times.

5.3.3 This specialist provision is complemented by the Community Mental Health Service and in-patient provision at the Meadows. These services are, however, provided for all mental health patients and not specifically for people with dementia and also have a limited capacity.

5.3.4 The Committee was informed that NHS treatment and support for people with dementia varies widely depending on the type of dementia. The Committee was informed that treatment and support is generally more accessible for people with a diagnosis for Alzheimer's Disease, which accounts for approximately 60% of all dementia patients. People with other forms of dementia, it was reported, often receive no specialist support from the NHS following diagnosis unless they have challenging behavioural issues that warrant intervention from the mental health team.

5.3.5 It was reported that in its early stages dementia is often classified as a social condition, and is not always therefore regarded as qualifying for medical intervention or further support. The Committee heard, however, that the need for support is often greatest at the point of diagnosis. One carer informed the Committee of the "devastating" impact such diagnosis has on both the patient and carer. It was reported that many people in the early stages of dementia are aware of their deterioration and able to comprehend the long term implications of the condition. It was felt that resources need to be re-directed in order to ensure all patients have access to support at this point and are informed of the support available during the course of the condition.

5.3.6 Furthermore, it was reported that though treatment and support for people with Alzheimer's is generally more accessible, there are still significant gaps in service provision. For example:

- support and treatment for people with Alzheimer's is often concentrated at the early stages of the condition before tapering off;
- only a small proportion of people with a diagnosis for Alzheimer's qualify for receiving medication to slow the progression of the condition;
- the diagnosis for many people is not clear cut, for example some people may have a mixture of vascular dementia and Alzheimer's Disease which may not be picked up; thereby restricting the support available to them

5.3.7 Services provided by voluntary and community sector organisations

5.3.8 The Committee was informed that the Alzheimer's Society, Pennine Care and Age Concern deliver a variety of peer support groups and community programmes. These groups / programmes complement NHS provision by offering support for people with all types of dementia and their carers at various stages throughout the condition.

5.3.9 These groups / programmes are set out in the tables below:

Services	Provider	Details
S.H.A.R.E.D (Support, Help, Access to Resources, Education for Dementia)	Alzheimer's Society	15 week programme, one day per week peer support and information group for both the carer and person they support. Aims to enable both the 'cared for' and carer to meet people who share similar circumstances and to learn more about ways of managing dementia and accessing the support available locally. (held every Thursday at Ada Kay Resource Centre, Bredbury and on Fridays at White Hill Resource Centre, Reddish)
Walk & Talk	Alzheimer's	A group for carers and the person they

	Society	care for – specifically to support those with a Vascular Dementia Diagnosis (alternate Wednesday's 11am-1pm at Etherow Country Park, Compstall). Two hours sessions focusing on walks around a lake. There are opportunities for discussion with outside speakers.
Coffee shop 'Drop in'	Alzheimer's Society	A weekly casual drop in for carers and the people they care for to meet other people in the same situation and contact outreach workers. Held at Romiley Life Centre, 3pmp-4pm
Daycare (access after assessment)	Age Concern	3 different weekly groups, providing support for people with mild to moderate dementia in a warm, friendly and stimulating atmosphere. (provision of activities like, reminiscence sessions, in house activities, games, speakers, entertainers, library, day trips, refreshments & lunch)
Carer Support Service		Providing respite in the person's own home
Stockport Dementia Care Training	Pennine Care	8 Weekly 2 hour education and training sessions to facilitate carers to manage their caring role in a more informed and confident way in order to reduce illness and stress
In2minds	Pennine Care	A 6 sessions, once in a fortnight post-diagnosis support group for people with early dementia and their carer

5.3.10 In addition the following other support networks are available:

Additional Peer Support Networks
• St Saviours Community Café' – Great Moor - Every Wednesday • Heald Green Carers Support – Heald Green Village hall – 4th Thursday every month • Reddish Carers Group – South Reddish Clinic – 1st Friday every month • Young at Heart – St Catherines Church – Heald Green – Alternate Thursday • Young at Heart – Our Lady's Church – Shaw Heath - Alternate Mondays • Oasis for Carers – Oasis – 1 Adswood Lane East – Every Tuesday • Learning for living – Wellbeing centre – Chestergate – Every Monday • Stockport Asian Elders Group – The Cellars – Heaton Moor

- Sunshine Circle – Quaker meeting house Stockport – Every Wednesday
- Poppy Club – Bramhall Methodist Church – Bramhall – Wed 1:30
- Stockport Action in Retirement group – Stockport Library – Friday 2:30

5.3.11 Furthermore Stockport has been selected as one of eighteen localities to become a national demonstrator site for a multi-agency peer support service model, which was proposed in the National Strategy. The model contains three strands:

1. User led peer support
Two peer support facilitators and four support workers will be in place to assist persons with dementia and their carers to organise the peer support they want, this can be in small groups, one-to-one, at home or in the community. The aim of the peer support is to create a social network and offer people an opportunity to get information and advice about how to live well with dementia.

2. Educate
The EDUCATE strand of the project aims to enable volunteers in the early phase of dementia to bring their skills and experience to raise awareness of dementia in Stockport and to educate others about their experience. These EDUCATES could be powerful in changing attitudes, raising awareness, changing perception and reducing the prejudice and stigma associated with dementia, thereby improving dementia care services.

3. Virtual peer support
Ten people with young onset dementia and their families will take part in an online peer support network via the internet. Participants will be provided with a free touch screen computer for the 12 months duration of the project. The touch screen is easy to use and will allow participants to contact other people with dementia and their families for support from their own home.

5.3.12 Organisations involved in the model include the Council, NHS Stockport, Pennine Care, Age Concern, Signpost for Carers and the Alzheimer's Society. The project will provide Stockport with an opportunity to be at the forefront of development and will act as a further drive for the improvement of local services.

5.3.13 The Committee welcomed this type of training and peer support. It was recognised that all of the above services offer an invaluable source of support for people with dementia and their carers, whilst also helping to enhance their quality of life. Furthermore the Committee felt that such services have a preventative element. They help to enhance patients' quality of life and can help patients to stay active and as independent as possible for longer and thereby reduce the incidents of lengthy and cost intensive hospital stays.

5.3.14 The Committee was informed that voluntary and community run services offer a low cost source of support for people with dementia. It was reported that there is a good supply of volunteers in the borough, and local Churches provide ideal local venues. The Bramhall luncheon group was cited as a particularly good example of this type of support; it is organised in conjunction with Bramhall United Reform Church and demand for the service has lead to an increase its meetings in recent months.

5.3.15 It was acknowledged, however, that provision is currently spread thinly across the borough and is particularly sparse in the areas around Cheadle Hulme / Cheadle and Heald Green. Members felt that this is a particular concern given the aging demographic profile of this area. The Committee felt that local provision of services is crucial in order to facilitate ease of access by all patients.

5.3.16 In addition Members felt that local specialist peer support services target a small close network of patients. It was felt that peer support services are most effective for people with an early diagnosis and access to them relies on patients and their carers accepting the condition and recognising the need for support at an early stage. It was noted, however, that many people with dementia and carers fail to acknowledge the need for support until the condition is in its more advanced phase and they are consequently unable to take full advantage of the benefits the above schemes offer.

5.3.17 The Committee felt that improving early diagnosis of dementia and signposting to support is key to increasing access to such services. It was acknowledged, however, that increased demand will further exacerbate challenges regarding the capacity of voluntary and community sector organisations.

5.3.18 Furthermore Members were concerned that many of the peer support groups offered in Stockport are marketed for “people with dementia and their carers,” which it was felt may deter the attendance of elderly people who live alone and those who don’t have an existing social network. It was acknowledged, however, that it is these people that are most vulnerable and would derive most benefit from peer support. The Committee felt that greater variety and flexibility in the type of support service provided would help services to reach more people.

Recommendation 5

The Committee recommends that:

i. Stockport NHS and Stockport Council (Joint Commissioning), in conjunction with the voluntary and community sector, carry out a gap analysis to identify demand for support across the borough and ensure provision is mapped to meet local demand.
ii. Stockport NHS consult with the voluntary and community sector on an annual basis in order to carry out up-to-date audits of services and help ensure provision of dementia services continue to meet

demand.

Recommendation 6
The Committee recommends that:

i. Further voluntary and community provision is encouraged and proactively supported by the Council as a low cost option to complement existing services and fill any gaps in provision (both in terms of location and type of service provided). In particular, the Committee recommends that the luncheon club operated in conjunction with Bramhall United Reform Church is considered as an example of good practice to be encouraged in other parts of the borough.
ii. The specific needs of BME groups are considered and support is tailored to meet their needs.

5.3.19 <u>The development of an integrated memory service</u>

5.3.20 The Committee was informed that dementia services have not been commissioned by the NHS as an integrated provision. Consequently services have developed independently in a piecemeal manner and are often not well co-ordinated, there is some duplication and provision is not equitable across the borough. Furthermore it is acknowledged that there is a lack of continuity in meeting the changing needs of people with dementia and carers through specialist and voluntary support as the condition develops.

5.3.21 The Committee received an overview of proposals for the development of an integrated model of diagnostic and support pathways for people with dementia. Key features of the proposed new model include:

- A more responsive system for diagnosing dementia where all health professionals are alert to the signs of dementia and proactively make referrals;

- Integrated specialist support services which bring together NHS and voluntary provision to reduce duplication and provide co-ordinated and holistic support for all patients pre-diagnosis, at diagnosis and post diagnosis

- Raised awareness throughout the NHS of the needs of people with dementia, enabling the provision of health care for dementia patients through mainstream services in addition to specialist input

- Three “hubs,” based in pre-existing community facilities, to act as single points of access for services, information and advice on dementia

- A dementia adviser role to provide specialist information and advice in the community, support a timely discharge from secondary care, and work in conjunction with GP practices.

5.3.22 The Committee welcomed the development of integrated provision. It was felt that the "hubs" would have an essential role in bringing together information relating to all dementia services and acting as a "gateway" to signpost patients and carers.

5.3.23 Furthermore by bringing together all forms of existing support into a single service, the Committee felt there would be greater opportunity to provide comprehensive and flexible support which can be tailored to meet individual needs.

5.3.24 In addition the financial challenges the NHS and other public sector organisations will face in the forthcoming years will further increase the need for joined up and rationalised service planning and delivery to meet increasing demand.

5.3.25 The Committee also felt that the title "memory services" may help to diffuse some of the negative stigma attached to "mental health services;" whilst the use of pre-existing community facilities would provide a less intimidating environment for patients and may encourage more people to seek advice at an earlier stage.

5.3.26 It was noted by the Committee that this vision supports the model of good practice identified in the National Audit Office report and promoted by NICE Guidance.

Recommendation 7
The Committee recommends that joint working between NHS and voluntary service providers is encouraged in order to provide a more integrated and comprehensive service. In particular, the Committee welcomes the proposed community memory services "hubs" and recommends that they are introduced and monitored during the 2010/11 municipal year, with a view to further developing the service across the borough

5.4 The role of the Stockport NHS Foundation Trust

5.4.1 <u>Current and planned provision for dementia care at Stepping Hill Hospital</u>

5.4.2 The majority of people with dementia will access general hospital care at some point during their illness. The National Dementia Strategy states that nationally up to 70% of acute hospital beds are currently occupied by older people and up to half of these may be people with cognitive impairment including dementia. Furthermore the Strategy

claims that the majority of these people are undiagnosed and not known to specialist mental health services. [18]

5.4.3 The close contact general hospitals have with undiagnosed dementia sufferers place them in a key position for helping to identify people with potential symptoms of the condition. General hospital staff have an important role in making appropriate referrals for accurate diagnosis and signposting patients to support services.

5.4.4 In addition general hospitals have an important role in ensuring patients with dementia receive a high quality of care whilst in hospital and are discharged as soon as appropriate with an effective care/support package.

5.4.5 Recent national research has, however, revealed that people with dementia typically experience worse outcomes in terms of length of stay in hospital and mortality than those without dementia who are being treated for the same illness or injury. A study carried out by the Alzheimer's Society in 2009 found:

- 57% of people with dementia admitted to hospital with a broken or fractured hip remain in hospital for 2 weeks or more, compared to an average stay of one week for patients without dementia.
- 47% of carers felt that being in hospital had a significantly negative effect on the general physical health of the person with dementia.
- 54% of carers felt being in hospital had made the symptoms of dementia worse.[19]

5.4.6 The unfamiliar and often noisy environment, cluttered ward layouts and poor signage found in many hospitals, often combined with multiple ward transfers, present particular challenges for people with memory and communication problems.

5.4.7 Meanwhile the report produced by the Alzheimer's Society noted that many nursing staff acknowledged difficulty in communicating with patients with dementia; and lack of appropriate dementia care in some hospitals resulted in patients' experiencing difficulty eating, drinking and with personal care. [20]

5.4.8 A key element of the National Dementia Strategy is to raise the prominence of dementia care in general hospitals. The Strategy includes proposals to do this by ensuring that hospital staff are equipped with the necessary knowledge and skills to recognise the symptoms of dementia; make appropriate referrals for diagnosis and

[18] Department of Health (February 2009) The National Dementia Strategy,p51
[19] Alzheimer's Society (2009) Counting the Costs: caring for people with dementia on hospital wards, px
[20] Alzheimer's Society (2009) Counting the Costs: caring for people with dementia on hospital wards, pxi

specialist support; and meet the needs of patients with dementia during their stay in hospital.

5.4.9 The Strategy calls for the commissioning of specialist liaison older people's mental health teams to work with nursing staff and healthcare professionals to:

- Provide a single point of referral for diagnostic testing;
- Support nursing staff in providing improved dementia care in hospitals;
- Ensure better co-ordination of hospital and community support services, to enable patients with dementia to be discharged from hospital as soon as is appropriate and to return to as independent and fulfilling life as possible following discharge.[21]

5.4.10 During the course of the Scrutiny Review, the Committee met with representatives from the Stockport NHS Foundation Trust to discuss the support and care available for people with dementia admitted to Stepping Hill Hospital.

5.4.11 The Committee was informed that a decision had been made not to recruit to the vacant post of specialist mental health liaison nurse at Stepping Hill Hospital following the departure of the previous post holder. Members were assured, however, that improving dementia care is a key objective for Stockport NHS Foundation Trust.

5.4.12 The Committee was presented with a copy of the Trust's Dementia Action Plan, which contains measures to:

- Improve dementia training for medical and nursing staff;
- Establish 'Dementia Champions' to raise the profile of dementia care throughout the hospital;
- Develop procedures for recording and monitoring patients' mental health needs;
- Promote greater user involvement in the development of dementia care;
- Monitor length of hospital stay for people with dementia and explore the development of support / advocacy services to promote early discharge;

It was reported that one member of the hospital's nursing staff is currently receiving in-depth dementia training. It is intended that this post holder will have a key responsibility for rolling out training and providing support for other staff in dealing with patients with dementia. Furthermore the Committee was informed that the Trust is currently participating in a national audit of dementia services, which it is hoped will further identify and support improvement initiatives.

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[21] Department of Health (February 2009) The National Dementia Strategy,p53

5.4.13 It was acknowledged, however, that though work to improve dementia care is underway it is at a very early stage. The Associate Director of Stockport NHS Foundation Trust explained that further work is required to establish an understanding of the extent of dementia as an issue throughout the hospital, the needs of patients and how existing acute services can be improved to satisfy any unmet demands. In particular he accepted that improved identification and recording of dementia will underpin the Trust's efforts to develop a comprehensive understanding of the issue and identify appropriate improvements.

5.4.14 The Committee welcomed the Trust's action plan as a reflection of its commitment to improving dementia care. However Members felt that the proposed initiatives will alone not have the capacity to impact significantly on the scale of the issue:

- The Committee was informed that at any one time approximately 400 in-patients at Stepping Hill Hospital have some form of dementia. These patients will have been admitted for a range of conditions and are consequently dispersed across wards throughout the hospital.
- It was noted that the former specialist mental health liaison post did not have the capacity required to provide an adequate service of the scale required.
- Consequently Members felt that though the current proposals for in-house training and 'dementia champions' will help to raise the profile of dementia, they will not have the sufficient capacity to provide the proactive identification, support and referral services required to significantly improve patients' dementia care in hospital and facilitate their early discharge.

5.4.15 <u>Proposed Specialist Mental Health Liaison Service</u>

5.4.16 The Committee received an overview of a proposed business case developed by Pennine Care for the commissioning of a specialist liaison service for older people's mental health issues, delivered through a joint partnership between Pennine Care Foundation Trust and Stockport NHS Foundation Trust.

5.4.17 The business case makes provision for the development of a Liaison team with responsibility for delivering specialist advice to health and social care professionals working in the acute sector, regarding mental health issues for patients primarily over 65 years.

5.4.18 There are three key elements to the service:

i. *Advice service for healthcare professionals* - to support healthcare professionals and provide practical nursing advice and support concerning the day to day care of mental health patients; including safety and risk issues, communication, behavioural and mental health symptom management, patients' timely discharge from hospital and referrals to specialist support services.

ii. *Education and training* - for general hospital ward staff to teach staff about how to assess, treat, manage and discharge patients with mental health needs.

iii. *Non emergency support service for in-patients on medical and surgical wards* – to include triage criteria designed to assess patients at an early stage, support the effective management of their needs from the outset and ensure streamlined continuity of support from admission to hospital through to a timely discharge into the community.

5.4.19 The Committee felt that a specifically commissioned specialist mental health liaison team is essential to significantly improve outcomes for dementia patients admitted to general hospitals.

5.4.20 It was reported that the service would expect to benefit approximately 600 referrals annually and would cost approximately £400,000 per year. The Committee felt this cost is a relatively small proportion of the total annual budget of £50million for older people's health services – particularly when the large number of hospital patients who would benefit from the service is taken into account.

5.4.21 Furthermore, as well as improving the quality of dementia care provided in the hospital, the Committee also noted that the proposals for a specialist mental health liaison team at Stepping Hill Hospital support Stockport NHS Foundation Trust's business objectives. By facilitating dementia patients' timely discharge from hospital, the Specialist Liaison Service would help to reduce demand for hospital beds and thereby potentially increase the number of patients being treated in hospital.

5.4.22 The National Audit Report on Dementia Services provides evidence of two Trusts, Leeds and Lincolnshire, which have already successfully implemented a similar specialist mental health liaison service. Both Trusts report positive outcomes in relation to the quality of dementia care provided for patients and cost effectiveness. The text box below provides further information on the outcomes of the Leeds' model taken from the National Audit Report:[22]

Leeds dementia care pathway
Following a review of dementia services in Leeds, the local NHS introduced: i. Psychiatric Liaison Service in the acute hospital; ii. rapid response community mental health team; iii. specialist short term mental health home care; iv. dementia specific intermediate care beds;

[22] National Audit Office (January 2010) Improving Dementia Services in England: An Interim Report, p22

The project received initial funding of £4.2million from the national Partnerships for Older People Project.

Early indicators show reductions in hospital length of stay of 4 days per admission for people with dementia for more than 3 years. This also released beds to help achieve other targets, such as the 18 week wait.

Recommendation 8
The Committee recommends that arrangement for internal monitoring, by Stockport NHS Foundation Trust Board, of progress in relation to the implementation of the Trust's dementia action plan is built into the plan. This will help to raise awareness and support for the plan at the highest strategic level.

Recommendation 9
The Committee acknowledges that a specialist mental health liaison service, in line with national good practice, would derive substantial benefits at a relatively low cost. The Committee recommends that such specialist mental health liaison service is commissioned by NHS Stockport during the 2011/12 financial year.

Recommendation 10
The Committee has found that evidence suggests there are benefits to be had from prompt hospital assessment and streamlined pathways through hospital for people with dementia. To this end the Committee recommends that:

i. Measures are implemented to speed up the time taken to carry out an effective hospital assessment of patients who are in an acute hospital;
ii. The pathway through hospital for patients with dementia is streamlined, and unnecessary transfers during hospital stay avoided.

The Committee welcomes this action at the earliest opportunity.

5.5 Dementia Services - Future Plans

5.5.1 The Stockport Dementia Strategy 2010-15

5.5.2 The Stockport Dementia Strategy sets out a vision for the improvement of local dementia care services over the next five years. The Strategy supports the development of an integrated model for dementia services and identifies specific priority objectives and actions for improvement.

5.5.3 The text boxes overleaf set out some of the key actions included in the Strategy, relating to the issues considered in this Scrutiny Review:

Measures to increase prevention and raise awareness and understanding of dementia

- Incorporate dementia awareness into public health campaigns focusing on healthy ageing and making sure people with dementia are not missed out in screening programs.
- Use every opportunity to raise awareness for dementia, like the National Dementia Awareness Week in July, the National Older People's day (1 October) and World Alzheimer's day (21 September).
- Update current information materials regarding dementia and make sure that they are accessible and understandable for everyone.
- Ensure information about dementia is provided at centrally located places like health care centres and libraries
- Investigate needs of BME groups to inform local information & advice activities and services.

Measures to increase early diagnosis and ensure the provision of adequate information and advice;

- Raise awareness about dementia in GP practices.
- Train primary care and social care staff and staff from voluntary organisations to detect dementia and signpost people with dementia and their carers to the appropriate services.
- Encourage people to consult their GP when they experience memory problems.
- Implement a joined up diagnostic pathway across primary care, community health care, social care, third sector and secondary specialist dementia care.
- Introduce the dementia adviser role.
  Create adequate peer support opportunities for people in their post-diagnostic stage to meet their needs
- Have a directory of services available for people with dementia and their carers in combination with other information services like FLAG (organisation For Local Advice and Guidance) and Age Concern etc.

Measures to improve dementia care in hospitals

- Improve staff training regarding recognising dementia, caring for and communicating with people with dementia and their carers.
- Implement a mental health or dementia liaison service to support ward staff in providing quality care for people with dementia and to organise a smooth discharge into the community.
- Recognise the role hospital staff can have in signposting people to appropriate support in the community.
- Ensure a good hand over when a person is referred to hospital and at discharge from hospital to services in the community to guarantee continuity and a person centred approach

5.5.4 The Committee noted that many of the actions outlined in the

strategy are supported by the recommendations arising from this Scrutiny review.

5.5.5 The Stockport Dementia Strategy has been devised, and will be monitored, by the Older People's Working Group (mental health), a sub-group of the All Our Tomorrow's Partnership. The Committee was informed that the working group is led by the PCT and comprises of stakeholders from the Council and voluntary and community sector. It was reported that the working group does not currently include representation from Stockport NHS Foundation Trust; however membership is due to be refreshed and representation from the Trust will be invited.

5.5.6 The Committee felt that the Older People's Working Group should be encouraged as an essential forum for multi-agency work to support the implementation of the integrated model set out in national guidance and the local dementia strategy.

Recommendation 11
The Committee recommends that:

i. All relevant stakeholders and dementia service providers sign up to the local dementia strategy and implement the appropriate actions in their organisations;
ii. The Stockport Older People's Working Group (mental health) takes a proactive role in monitoring the implementation of the Strategy;
iii. An annual report on performance in relation to the actions contained in the local dementia strategy is presented to the Health and Wellbeing Partnership Board.

Recommendation 12
The Committee recommends that membership of the Stockport Older People's Working Group (mental health) is refreshed to include representation from Stockport NHS Foundation Trust, in addition to all other relevant stakeholders from the PCT, Pennine Care, Stockport Council and the voluntary and community sector.

5.5.7 <u>Target / performance monitoring for Dementia Services</u>

5.5.8 During the course of the review the Committee learnt that there are no national targets for dementia services. It was reported that though the National Dementia Strategy provides a generic framework for statutory and voluntary agencies to work towards, the document is not target driven.

5.5.9 The Committee and representatives from the PCT and Pennine Care felt, however, that targets provide an important incentive to drive forward progress. In addition it is felt that securing the commitment of all relevant agencies to deliver a set of targets will help to forge a

shared vision across statutory and voluntary agencies and guide co-ordinated partnership work.

5.5.10 Furthermore NICE Guidance and the National Audit Office's Interim report on "Improving Dementia Services" both promote the development of a performance framework as essential to the delivery of an effective integrated memory service. The National Audit Office's report specifies the need to evaluate the value added by services in order to make a case for new services or changes to existing ones.[23]

5.5.11 The Scrutiny Committee was keen to encourage the development of a local set of targets, which it was proposed all NHS and voluntary service providers would be asked to sign up to. It was suggested that performance data in relation to these targets would be reported to and monitored by the Health and Wellbeing Partnership Board and All Our Tomorrows Partnership Board.

5.5.12 The Committee felt that a carefully constructed set of shared targets, focussing on specific priorities for improvement would provide a proactive way of raising the profile of dementia services and encourage joint working and targeted action. In addition it could be used to support the development of an integrated memory service by helping to forge a shared vision and focussed action plan.

Recommendation 13
The Committee recommends that:

i. A local set of targets and performance indicators focusing on specific priorities for improvement in relation to dementia services, is developed and agreed by the Health and Wellbeing Partnership Board;
ii. All NHS and voluntary service providers are encouraged to sign up to the targets; and performance is reported to the Health and Wellbeing Partnership Board.
iii. The targets are reviewed on an annual basis.

Recommendation 14
The Committee recommends that a further meeting is held in twelve months time, with all stakeholders, to monitor progress towards implementing the recommendations contained in this review and to assess their outcomes.

[23] National Audit Office (January 2010) Improving Dementia Services in England: An Interim Report, p9

6. Appendix – the Stockport Dementia Strategy 2010-2015

Dementia Strategy

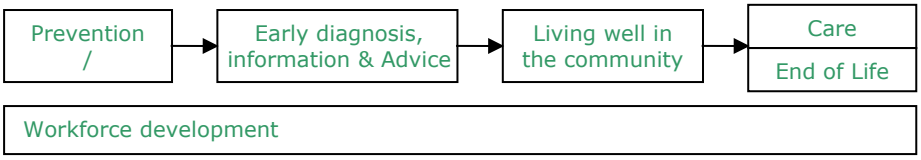
Out of the Shadows & Living Well with Dementia in Stockport

DRAFT 04-02-2010

V1.0	**Joint commissioning lead and manager**	
V2.0	**Stockport Older People's Working Group**	**20-01-2010**
V3.0	**Consultation key stakeholders**	**Till 8th March 2010**
V3.0	**AOT, PCT board, SMBC management team**	**Till 22nd March 2010**
V4.0	**Final version**	

Joint Commissioning Strategy Stockport

April 2010 – March 2015



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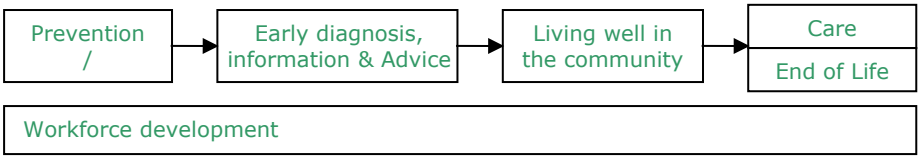


Joined up working

9. Link to other strategies and priorities
   - 9.1 Carers' Strategy
   - 9.2 Personalisation
   - 9.3 Housing Strategies
   - 9.4 Telecare / telehealth Strategy
   - 9.5 Mental Health Strategy
   - 9.6 Dignity in care
   - 9.7 Mental Capacity Act and safeguarding
     - 9.7.1. Mental Capacity Act
     - 9.7.2 Safeguarding and the protection of vulnerable adults
   - 9.8 Older People's Joint Commissioning Strategy

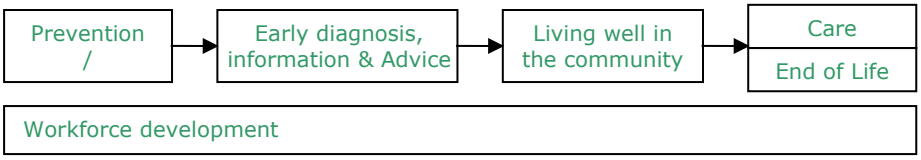
10. Pathway, actions and performance targets

Appendix

- Implementation plan

- Objectives National Dementia Strategy

- Joint Strategic Needs Assessment – Dementia Stockport



1. Introduction

Dementia is a long-term condition with high impact on a person's health, social circumstances and family life.

It is estimated there are currently 3,440 people in Stockport with dementia. Of this group between 50 and 65% will never have a confirmed diagnosis. A third of the total group (3,440) is men and two-third is women. The prevalence of dementia increases with age, 40% of those with dementia are aged 85 years or more. Assuming that prevalence rates remain the same and if the population changes as expected, then by 2015 there will be to be an additional 400 people in Stockport aged 65 and over with the condition and by 2025 there will be an additional 1,200 people living with dementia. There will also be an increased number of people aged under the age of 65, diagnosed with dementia.

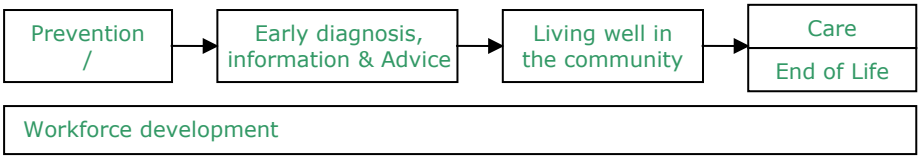
The Department of Health launched the first ever National Dementia Strategy, Living well with dementia, for England in February 2009. The national strategy sets out the direction of travel to deliver the transformation of dementia care in England for the coming 5 years.

The overarching national goal is for people with dementia and their carers[24] to be helped to live well with dementia, no matter the stage of their illness or where they are in the health and social care system. The vision to achieve this is divided in three parts:

- To encourage help-seeking and help-offering by changing public and professional attitudes, understanding and behaviour towards dementia.

- To make early diagnosis and dementia treatment the rule rather than the exception. This will be achieved by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can make an accurate

[24] In this document we use the word 'carers' to address family and friends who provide unpaid care and support and 'care workers' to address paid workers in dementia care.

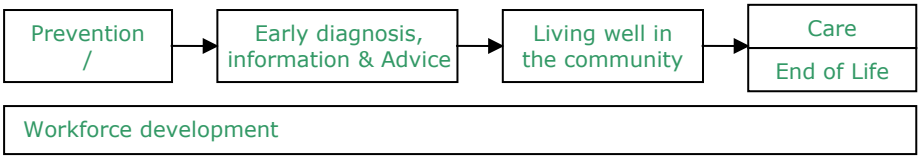


diagnosis, communicate the diagnosis sensitively to those affected and provide individuals with immediate treatment, care and peer and professional support as needed.

- To enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

Within these three themes the government has identified 17 specific objectives to act upon nationally and locally (see appendix 1 for an overview of the objectives in the National Dementia Strategy).

In Stockport we have already achieved some of the objectives mentioned in the National strategy. We have for example a highly evaluated Stockport Dementia Care Training, we offer carer breaks, we have a dementia treatment clinic in secondary care, we offer a variety of peer support and day care services, we have already a multi-agency and joined up approach in offering dementia care services in our borough, there is a palliative service available, we have a social care liaison post, we offer telecare facilities, we deliver extra care housing for people with dementia and the HIT-team is integrated with the CMHT (Community Mental Health Team) team. We are currently working on collating a directory of service, we are rolling out more peer support opportunities as part of a national Department of Health Demonstrator Site pilot and we are developing more services for people with young onset dementia. Also a shared pathway between primary and secondary care is in development to improve the assessment and diagnostic process and post-diagnostic support in a timely manner. However, not all initiatives are well resourced, some lack the capacity to meet the current and future demand and the funding isn't secured for all services. Also, not all services are provided in a joined up approach, we lack a hospital liaison service and the service provision in general is not equitable across the borough and is not always meeting the



specific needs of groups like people with learning disabilities and Black and Minority Ethnic (BME) groups in our borough.

Since the launch of the National Dementia Strategy, agencies in Stockport have worked together to develop Stockport's own Dementia Strategy. This strategy has been devised following consultation with key stakeholders in health, social care, housing, supporting people, independent care sector organisations and voluntary organisations and a separate consultation with people with dementia, their carers and the public.

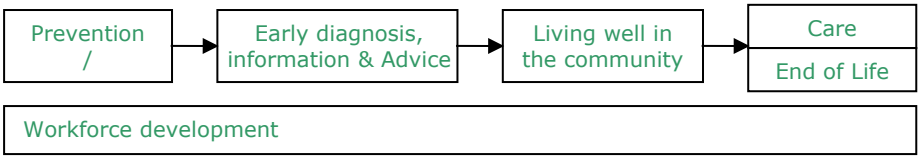
Together we have identified the following **9 priority areas** for Stockport:

- ***Better understanding of dementia***: for people affected by dementia, either personally or as a carer, it is important to know what dementia is, how to manage the condition and where to go for help and information. We would like to avoid people having to tell their story over and over again and provide pro-active signposting and support through the whole health and social care system.

- ***Raising awareness***: through better awareness we would like to reduce the stigma and misunderstanding associated with dementia and ensure that people in Stockport are well informed about dementia and know how best to support people they know with dementia.

- ***Early diagnosis***: we think there should be more opportunities to visit a professional if people are worried about their memory, or the memory of someone close to them. We want these services available as soon as they become aware of a problem, in order to get an early diagnosis and be offered appropriate support as soon as possible.

- ***Living well in the community***: most people want to continue living in their own homes or in other forms of housing in the community



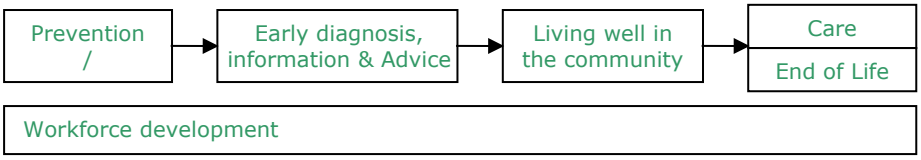
that meet their needs and where they feel safe and comfortable for as long as they can. We want to support people with dementia to stay at home as long as possible by providing a range of services and support, including equipment, financial advice, care, activities, day services and end of life care, to meet their personal needs. We would also like to offer people choices in terms of high quality, sustainable homes and neighbourhoods. Furthermore, we recognise the need to offer advice, information and support to carers to assist them in being able to support the person with dementia to remain living independently at home or in a supported accommodation of their choice.

- ***Carers' support***: taking care for someone with dementia can be challenging without the right support. People should have access to flexible services meeting their needs, timely information & advice and the chance to meet and share information and experiences with people who also care for someone with dementia.

- ***Special groups***: people with dementia often fall into different groups, such as younger people (under 65) with dementia, people with learning disabilities who also have dementia and people with dementia from Black, Minority and Ethnic (BME) groups with dementia. We feel it as important to meet the specific needs of each group and individual as necessary.

- ***Quality care in hospital***: sometimes it is necessary for people with dementia to go to general hospitals for more specialised care for other conditions they suffer. In these situations it is important that people with dementia are treated appropriately and with the right attitude, also taking the carers needs into account.

- ***Quality in care homes***: If people with dementia need to go into a care home, they should receive high quality care (including end of life

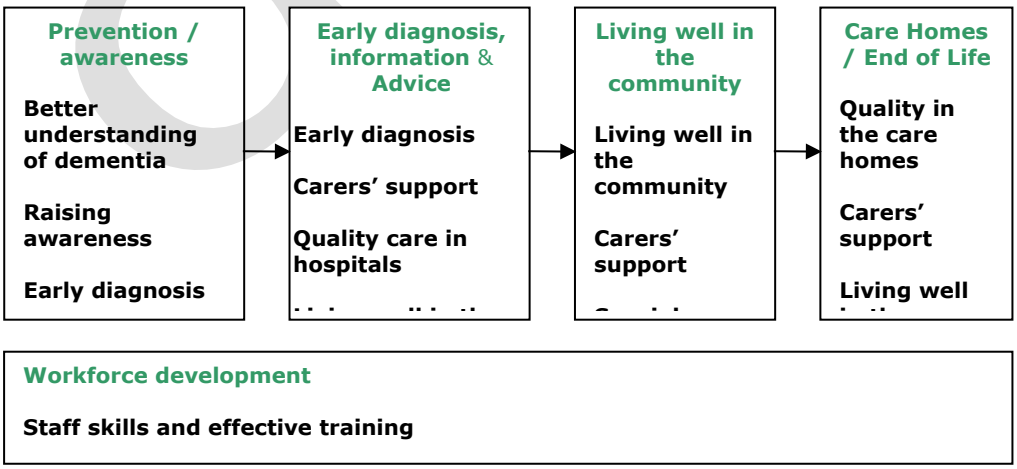


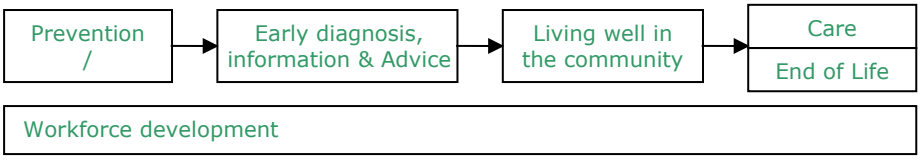
care) from people who offer person-centred care, understand their challenges and have the skills to respond appropriately.

- ***Staff skills and effective staff training***: people with dementia and their carers will use mainstream health and social services. We think it is important that all social care and health care staff are able to recognise and understand the implications of providing care to a person with dementia, as well as taking into account the needs of their informal carers. Health and social care staff also have a responsibility for signposting people to the right services and therefore need an understanding of what services are available.

Overall, we want our services in Stockport providing quality and continuity, located where the need is, easy accessible, personalised and regularly evaluated by professionals, carers and service users.

This document sets out how we would like to improve our dementia care services in Stockport over the next 5 years and how this relates to our 9 priority areas within the following model:





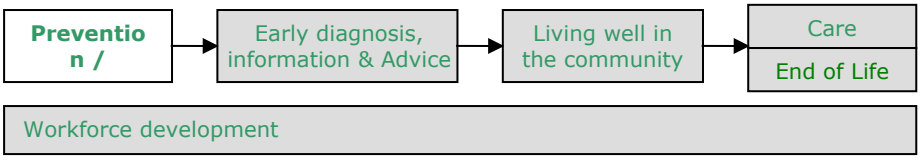
2. General Principles & Values of Dementia Care in Stockport

We expect all providers of dementia care in Stockport to meet the following principles:

- work in partnership with and take account of the needs of people with dementia and their carers;
- health organisations, the council, independent and voluntary sector organisations work in partnership, follow clear pathways, share and make good use of available resources to improve the health and well-being of people with dementia and their carers;
- support people's independence and ability to live well in the community for as long as possible either in their own home or in supported accommodation meeting their needs;
- offer person-centred services tailored to individual needs, promoting choice and care at home or close to people's home;
- all staff (including volunteers) demonstrate dignity and respect;
- services provided are aimed at reducing inequalities, are inclusive and not discriminatory;
- all dementia care services are regularly evaluated by service users and their feedback used for continuous service improvement.

As commissioner we will:

- regularly consult people with dementia and their carers to ensure we take account of their needs;
- support equality in access and service provision;
- commission quality and state of the art services and regularly monitor actual provision against agreed outcomes;
- encourage best use of available resources across the borough;
- facilitate working in partnership between providers of dementia care;
- guarantee consistency with priorities of the Health and Well-being Partnership Board and All Our Tomorrow's Partnership Board
- facilitate training and awareness raising for dementia.



3. Prevention & raising awareness and understanding for dementia

People told us:
* *'Friends drift off – they don't know how to handle it'*
* *'Formal carer doesn't understand the illness'*
* *'Invest in raising awareness'*

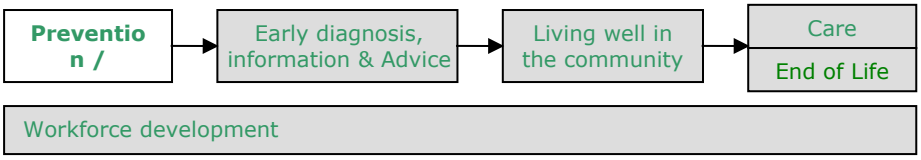
3.1 What is dementia? - Some background information

Dementia UK (2007)[25] reported the following summarised information about dementia:

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, mood changes and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease, Vascular dementia, Lewy Body disease, Parkinson's disease and Fronto-temporal dementia. Dementia can affect people of any age, but is most common in older people. One in 5 people over 80 has a form of dementia and one in 20 people over 65 has a form of dementia at the moment and these prevalence figures will raise. Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia. People with learning disabilities are a group at particular risk.

Dementia is a progressive condition. This means that the symptoms become more severe over time. Although the condition is terminal, people can live with dementia for seven to twelve years from diagnosis. The way each person experiences dementia, and the rate of their decline, will depend on many factors – not just what type of dementia they have. However, for most people a diagnosis of dementia has the

[25] Dementia UK (2007). A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society.



same devastating impact on the person with dementia and their carers. Understanding of how the condition progresses and what to expect, can be useful in helping someone with dementia anticipate and plan for their future.

3.2 Health promotion & prevention of dementia

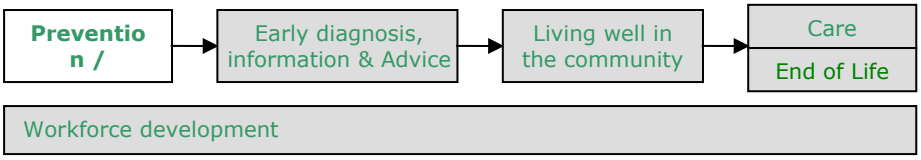
Dementia is difficult to prevent because we still don't know exactly what causes dementia. However, we do know that people who have vascular dementia, the second most common form of dementia (after Alzheimer's disease), may be able to prevent further decline by lowering their risk of heart disease and stroke, and controlling high blood pressure and high cholesterol which are key risk factors. [26]

The current evidence suggests that up to 50% of dementia cases may have a vascular component.[27] And 10% of the dementias are related to alcohol.[28] The related preventative actions people can take are also activities to support healthy ageing in general, and therefore everybody might benefit from the following lifestyle interventions:

losing excess weight
limiting alcohol
healthy eating
quitting smoking
Physical activity
social involvement

Health and social care staff also have to be aware of possible extra attention that might be needed to ensure people do not miss out on prevention programs like flu-vaccination or screening programs due to their condition.

[26] Factsheet Vascular Dementia, Alzheimer's Society.
[27] National Dementia Strategy (2009), pp. 27.
[28] Joint Commissioning Framework Dementia, June 2009, pp. 14.



Besides the focus on living a healthier life for longer, it is also important to stimulate personal identity, involvement in own care and the development and assisting people to maintain a strong support network. This will all positively influence the quality of life for people with dementia and their carers.

3.3 Supporting health & well-being for carers

Another aspect of prevention and health promotion is around the needs of carers. Dementia has an impact on the quality of life of everyone in the family and there is a lot of evidence that carers experience high levels of depression and physical health problems as a result of the burden of caregiving. They often ignore their own health needs in favour of those of the person for whom the care, they may become exhausted, have poor physical health, have feelings of guilty and feel isolated.[29] Also becoming an 'ex-carer', e.g. when the person they cared for has to go into a care home or has died, is a particular stage in a carer's life that needs special attention as there is a risk of social isolation and feelings of depression.

Carer: 'there is no support when I am down or struggling with my own needs'

Carer:'I have circulation / blood pressure problems from lack of sleep due to caring for my partner'

Carer: 'I would like to have a regular health check'

It is vital that carers are identified and supported at the earliest stage possible so that they have access to the support needed. GPs are often the first point of contact which is why they and their practice teams have a pivotal role to play in the daily lives of carers.[30]

3.4 Raising awareness & informing the public

Currently, 700,000 people in the UK and around 3,500 people in Stockport live with dementia. Many people know somebody with dementia. Public and professionals do not always know enough about dementia to

[29] NICE (2006) Dementia: supporting people with dementia and their cares in health and social care – Clinical guideline 42, London.
[30] Supporting Carers: an action guide for general practitioners and their teams. The Princess Royal Trust for Carers & Royal College of General Practitioners (2009).

recognise it, to understand the impact of dementia on peoples life, to direct people to the right services and to support people with dementia and their carers properly.

There is a stigma associated with dementia and the people we consulted reported feelings of loneliness and isolation because their friends and family have drifted off.

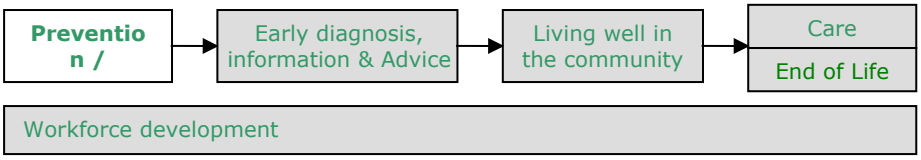
Good practice: information bus during national dementia awareness week

There also needs to be better understanding and support from employers with regard to the challenges people with young onset dementia and their carers experience.

From our consultation event in the Asian Heritage Centre we learnt that BME groups lack information about what dementia is and what services are available. Finally, special attention was paid, at the service users and carers' consultation, to people with a sensory impairment having dementia. We need to ensure that our awareness campaigns and information materials are accessible to people with any type of disability.

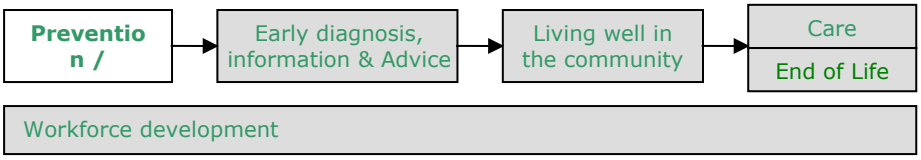
Actions Prevention & raising awareness and understanding of dementia

- → Incorporate dementia awareness into our public health campaigns focusing on healthy ageing and making sure people with dementia are not missed out in screening programs.
- → GP practices: review vascular and other modifiable risk factors for dementia by looking at the Quality and Outcomes Framework (QOF) indicators: Coronary Heart Disease (CHD 1), Stroke 1, blood Pressure



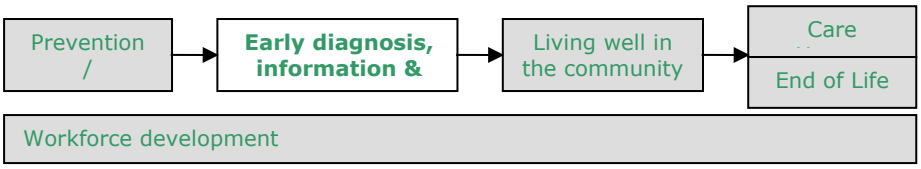
(BP1) and promote a healthy lifestyle (Joint Commissioning Framework Dementia).

- → Regular health checks as part of health facilitation for people with learning disabilities (NICE-guidance).
- → GP practices: identification of carers e.g. via QOF-register and regular assessment of carers' health needs when requested by carers.
- → Offer psycho-education, peer-support, carers breaks, counseling – see also chapter 5.
- → Local campaigns to raise awareness for dementia and inform the public how best to support people with dementia and their carers in Stockport. This campaign will feed in to the national awareness campaign that is being developed.
- → Use every opportunity to raise awareness for dementia, like the national dementia awareness week in July, the National Older People's day (1 October) and World Alzheimer's day (21 September).
- → Train mainstream staff to recognise dementia and understand needs of the person with dementia and their carers.
- → Implement EDUCATE project. The aim of this project is to enable volunteers in the early phase of dementia to bring their skills and experience to raise awareness of dementia in Stockport and to educate others about their condition. EDUCATErs can be very powerful in changing attitudes, raising awareness, changing perceptions and reducing prejudice and stigma associated with dementia.
- → Update our current information materials regarding dementia and make sure that they are accessible and understandable for everybody.
- → Ensure information about dementia is provided at centrally located places like health care centres and libraries
- → Incorporate a role for raising awareness and informing the public within the memory clinic, dementia champions and dementia adviser posts.



→ Investigate needs of BME group to inform local information & advice activities and services.

Agreed outcomes in 2015 including performance measurements:



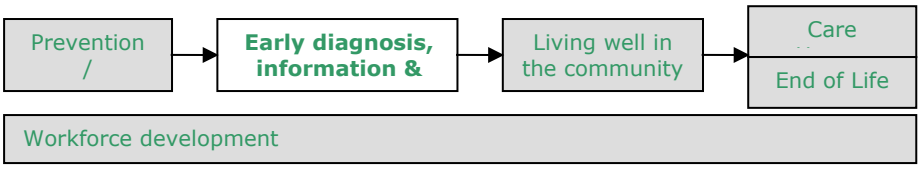
4. Early diagnosis & adequate information and advice

People told us:
* *'It takes courage to ask for a diagnosis'*
* *'My GP gave me a speedy initial diagnosis'*
* *'Specialist services are brilliant'*
* *'GP didn't take me seriously'*
* *'Just ageing' said my GP'*

It is essential that all people with dementia have early access to a care pathway that delivers a rapid and competent specialist assessment, an accurate diagnosis, appropriate treatment and sensitively communicated information about their condition and the services available to them. A diagnosis is the first step in developing a holistic care plan for both the persons with dementia and the people who care for them to support their quality of life throughout all stages of the dementia. Although it is devastating to get the diagnosis of dementia, people also told us *'it was a shock, but also good in a way because at least we knew what we were dealing with'.*

Stockport's GP practices have identified in total 1,500 people on their disease registers for dementia. However, national estimates (POPPI database) suggest that there is currently significant under diagnosis of this condition in primary care, and that in fact there are an estimated 3,500 people aged 65+ with dementia in the Stockport area. This figure seems to be supported by data from Alzheimer's Society stating that there are currently at least 3,201 people in Stockport living with dementia. However the number of sufferers is maybe even 15% higher than had been estimated, according to the Dementia 2010 Report that was launched in February 2010.[31] This means that still a lot of people in our area are not known in our systems and we are not sure if they have access to the available dementia care services either.

[31] Luengo-Fernandez, R. et al., Health Economic Research Centre, University of Oxford for the Alzheimer's Research Trust. Dementia 2010 – The economic burden of dementia and associated research funding in the United Kingdom, February 2010.



Currently in Stockport, only two-fifth of those people with dementia receive a formal diagnosis or has contact with specialist services at any time of their illness. National evidence shows that such diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed or are reduced. Locally, already good work has been done to diagnose people with dementia earlier on.

We feel it as important to further encourage people to get an early diagnosis and to support professionals like GPs to recognise early symptoms of dementia and initiate a timely assessment process.

Early diagnosis is especially important for people with Alzheimer's disease. The earlier someone with Alzheimer's Disease starts medication, the more beneficial these medications are e.g. helping some people to maintain daily function and quality of life as well as stabilising cognitive decline. [32]

Good practice: Support in early dementia DVD

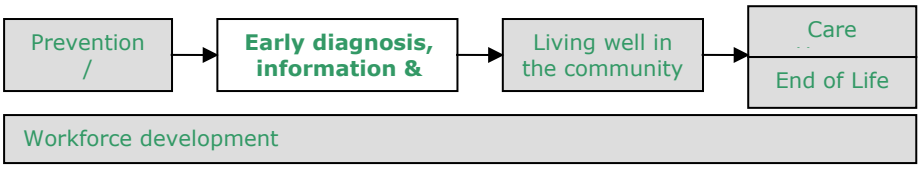
An early diagnosis might also be important to exclude other diagnosis presenting with similar symptoms to dementia.

In addition we want to encourage people to get an early diagnosis to give them and their carers the opportunity to receive the information and (peer-)support they need and prepare themselves for possible situations in the future.

4.1 Role of Primary Care

For the majority of people, the first opportunity for individuals or their families to raise concern over changes in memory or behaviour is within primary care. In the majority of cases, this is triggered through discussion with General Practitioners, Practice Nurses, District Nurses, Care workers and Social Workers, for example.

[32] Dementia Care Knowledge Centre, Alzheimer's Society; accessed on 5th November 2009.



General Practitioners (GPs) have a crucial role in ensuring that early concerns are detected and responded to, and not misattributed to the symptoms of old age, and that the needs of younger people with dementia are addressed. Although we have a higher than average rate of detecting young onset dementia in Stockport compared to national figures, it is still an area to improve.

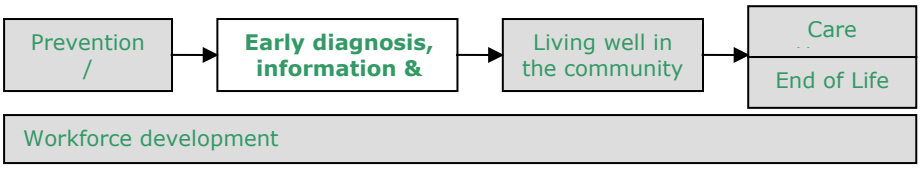
According to the National Dementia Strategy, only 31% of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia, a decrease since the same questions was asked 8 years ago. Nurse practitioners in Stockport also flagged up they want better training to assist them in recognising dementia and supporting people with dementia and their carers in the practice.

The GP-practice is not only an important key-factor in the diagnostic process, the practice also has an important role in following the person with dementia and their carers through the different stages of dementia and in ensuring all support is available for their health and well-being to avoid crisis situations. Dementia is a medical disorder and should be managed like any other serious long-term illness[33], including conducting regular health checks (for the person with dementia and their carers), ensure people with dementia attend screening programs, start preventive actions and signposting people to existing information, advice and support services in the community.

4.2 Role of Secondary Care

Stockport's secondary care dementia treatment clinic is highly valued by service users. However, not every person with dementia has access to this diagnostic service and some people could be referred much earlier to this clinic by their GP. There is a need for a whole system approach to ensure that early signs of dementia are detected, diagnosed and treated, as well as providing ongoing monitoring and support for those living with

[33] Nuffield Council on Bioethics, Dementia: ethical issues. October 2009.



dementia. Special attention is needed to make sure people with young onset dementia and people with learning disabilities have access to the right treatment at the right time.

Due to the high demand for diagnostic and treatment services, it will be a priority in Stockport to make sure specialist services are utilised in the best way with a focus on specialised diagnosis, starting people on treatment if applicable and referring them back with a care plan to primary / community care for follow up accordingly to individual needs.

With a focus on early diagnosis and awareness raising for dementia increased demand on secondary care services is inevitable. Partnership working between primary care, social care, secondary care and the third and voluntary sector will be even more essential to ensure a smooth pathway to and from secondary care to make the best use of available specialist resources.

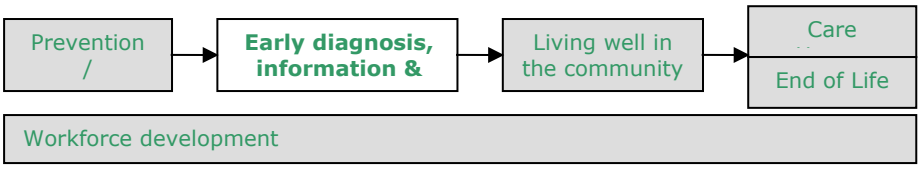
4.3 Information and advice pre-diagnostic

People who are worried about their memory should have easy access to information about the early signs of dementia and signs of other conditions related to memory loss. They also need to be aware of prevention strategies and how to seek help.

To support an early diagnosis we have to make sure people feel able to visit their GP to discuss their memory problems. As it takes a lot of courage to ask for a diagnosis, we need to do everything possible to support people in this uncertain time. We envisage that the dementia adviser has a key role in explaining the importance of diagnosis and if necessary could accompany somebody on a visit to their GP.

4.4 Post-diagnostic information & advice

As with every other long-term condition people prefer and expect to have regular follow-ups by someone who pro-actively checks that everything is alright, that all possible support is in place and that people are coping. This could be a role for a dementia adviser. Currently, information, advice and signposting are available in Stockport and are mainly provided by



voluntary organisations. However, this role is not embedded in a clear dementia pathway and is not pro-actively and regularly provided to all people with dementia and their carers. Currently, it is up to the people themselves to seek help. If people don't know where to go to or don't ask for help, they won't get the support they need. This causes delays in accessing services, leads to crisis situations and/or reduced quality of life.

In the post-diagnostic stage, after being discharged from secondary care, we envisage a pathway containing the following building blocks:

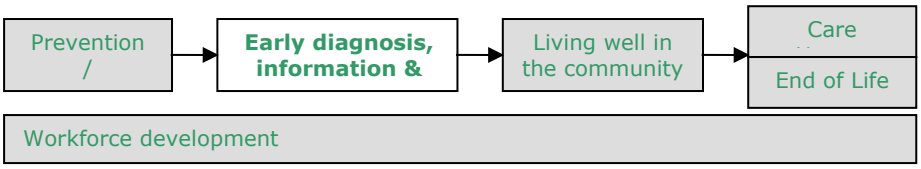
- A supportive GP, regularly checking the health and well being of the person with dementia and their carers
- Provide training by Stockport Dementia Care Training Partnership for carers - to inform them and prepare them for their caring role and to meet others in a similar situation
- A peer support group following diagnosis
- A named dementia adviser in the community to provide people with dementia and their carers with quality information and signpost them to services tailored to their individual needs. The dementia adviser will also fulfil a role in empowering people to access the information they need, promoting independence, self-help, well-being, choice and control and support people to anticipate future needs. The dementia adviser therefore needs to have a good insight into what is available in Stockport and needs to collaborate with other health and care professionals to maximise the outcome for the person with dementia.[34]

Actions: Early diagnosis & adequate information and advice

→ Raise awareness about dementia in GP practices.

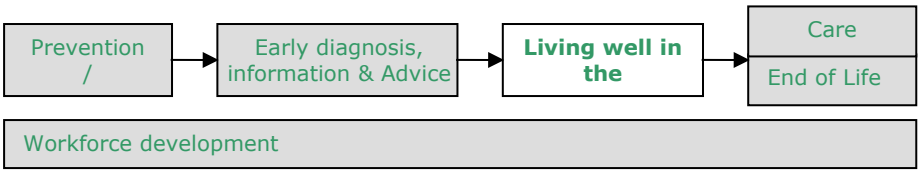
→ Train primary care and social care staff and staff from voluntary organisations to detect dementia and signpost people with dementia and their carers to the appropriate services.

[34] Alzheimer's Society factsheet dementia advisor.



- → Improve registration of people with dementia on the QOF database.
- → Increase numbers of carers registered on QOF being invited for regular health checks.
- → Create a signpost role for all mainstream services including voluntary organisations to information and advice services and encourage people to consult their GP when they experience memory problems.
- → Implement a joined up diagnostic pathway across the following sectors: primary care, community health care, social care, third sector and secondary specialist dementia care for people with dementia in general including young onset dementia.
- → Develop and implement a specific pathway for people with learning disabilities and dementia.
- → Introduce the dementia adviser role to provide a specific information and advice function in the community and to support a timely discharge from secondary care in conjunction with regular follow up by GP practices for the person with dementia and their carers.
- → Commissioning adequate capacity in specialist dementia services in secondary care to meet demand.
- → Create adequate peer support opportunities for people in their post-diagnostic stage to meet their needs (age / situation specific) based on the results of the dementia demonstrator site projects.
- → Have a directory of services available for people with dementia and their carers in combination with other information services like FLAG (organisation For Local Advice and Guidance) and well-check from Age Concern etc.
- → An up to date guidance on prescribing incorporating the latest NICE guidelines and recent research findings regarding anti-psychotic drugs.

Agreed outcomes in 2015 including performance measurements:



5. Living well with dementia in the community

5.1 Community care

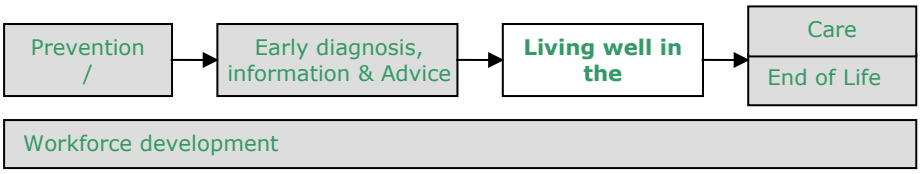
People prefer to remain independent for as long as possible in their own homes. This is even more important for people with a dementia, because a familiar environment helps someone with dementia to remain independent for longer as well as helping them to feel more confident. Equally, forms of specialised and supported housing can offer this familiarity and feeling of independence.

The main aspects of living well with dementia in the community are:

- Prevention of social isolation
- Support to keep skills, meet others and feel secure
- A variety of support for carers to be able to fulfill their role
- A safe environment to live at home including adaptations and telecare support
- Support at home delivered by skilled staff with the 'right' attitude
- Risk management: people with dementia finding the right balance between living safely in their own home with the right support or choosing for moving into a specialised provision of care option
- Support people to recognise and acknowledge their current and future needs (insight in their condition and challenges) and support them to decide upon accordingly
- Choice in terms of specialist and supported housing options including Extra care.

5.2 Personalised care and support to live well with dementia

For many people getting a diagnosis of dementia is as a shock, turning their world upside down. However, more examples showing that people can live a good quality life despite being diagnosed with dementia are being highlighted in the media. Key factors seem to be keeping active, getting the right encouragement and support and finding the right coping



strategy that works for each person individually and to manage the situation around them.

To provide what people need, requires flexibility, continuity and above all creativity (person-centered care). '*Every person is unique'* and therefore every care package should be tailored to the needs and the world of the individual. This can be a real challenge for organisations.
However with the role out of personal budgets, it is becoming possible for people to have individual care packages tailored to their individual needs. It is really about finding the balance. In the coming years use of personalised budgets and giving people more control about the provision of services will be further developed within dementia care.

5.2.1 Young Onset Dementia

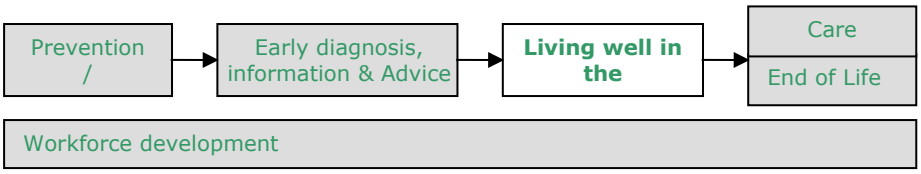
Younger people with dementia have different needs from older people diagnosed with dementia.

They may:
- Have dependent children
- Be in work at the time of diagnosis
- Have heavy financial commitments
- Find it difficult to rationalise losing skills at such a young age
- Find it difficult to access appropriate information and support.

Source: Alzheimer's Society

Getting dementia at a younger age has major implication for someone's own life and the family and friends around them.

People with young onset dementia (dementia commencing in people under the age of 65) told us that most of the current services are focused on older people. People with young onset dementia want different support for themselves and for their families including support with changes in work life, planning for the future and financial advice.



At the moment in Stockport, there are limited services available for people with young onset dementia even though we seem to have a higher numbers than the national estimated prevalence. We therefore need to review this area of care provision and look at how it could be more effectively resourced. This requires an integrated approach across a range of services and between services for people under and above 65 years old.

5.2.2 People with learning disabilities and dementia

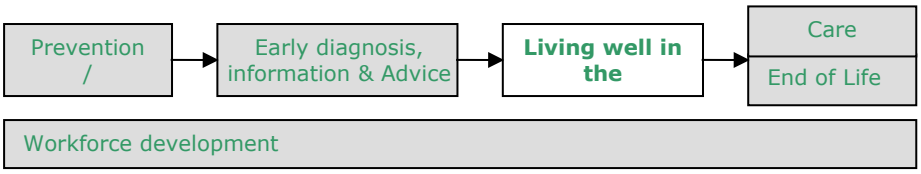
One fifth of the people with learning disabilities have Down's syndrome. People with Down's syndrome have an increased risk of developing Alzheimer's disease. The prevalence of dementia in people with other forms of learning disability is also higher than in the general population. As the population of people with a Learning Disability now have a higher life expectancy and is ageing, we can expect the prevalence to further increase.

The principles that apply to people without a Learning Disability who have dementia apply to those who do, including routine, familiarity, staff who are knowledgeable about the condition and an appropriate use of medication.

We need to further develop a clear pathway for (early) diagnosis and support for people with a learning disability with clarity about who (old age psychiatry and learning disability psychiatry) is providing what.

5.2.3 Black and Minority Ethnic Groups and dementia

It is predicted that the number of people from Black and Minority Ethnic (BME) groups with dementia will rise as the population ages. Also a higher percentage of people amongst BME groups, compared to the general population, are predicted to have young onset dementia. Through a consultation at the Asian Heritage Centre it is apparent there is not always a clear definition of dementia in other languages and cultures. In partnership with the BME communities we need to invest in awareness



raising and development of appropriate and accessible services and support for BME groups and their carers.

5.2.4 People with dementia and sensory impairment

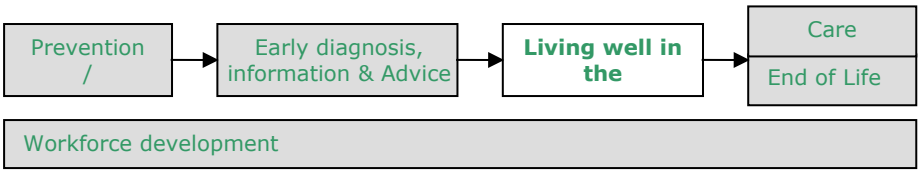
The outcome of the consultation with service users and carers made us aware that our information provision is not always accessible for people with sensory impairments. These impairments may mask the development of dementia and make early recognition of dementia complicated. Research[35] shows people with (visual) impairments also experience: disorientation, loss of independence, accepting multiple losses, risk of isolation, hallucinations, and difficulties to access services. Hearing impairment is likely to expose or exacerbate the symptoms of dementia, thereby promoting its diagnosis or resulting in so-called excess disability.[36] Research also shows that people with hearing impairments and mild dementia improve when hearing loss is restored.[37]

Service users in Stockport told us services are not totally accessible or suitable for people with a sensory impairment and a dementia. We envisage that awareness raising, joint working, promoting independence via personalised care and accessible information materials can be the answer to meet the distinct and particular needs that may not currently be adequately met in the community.

35 King's College London, The experiences and needs of people with dementia and serious visual impairment: a qualitative study. November 2008

36 Uhlmann, F. et al, (1998). Relationship of hearing impairments to dementia and cognitive disfunction in older adults. *JAMA.* 1989; 261 (13), pp.1916-1919.

37 Allen, H., et al (2003) The effects of improving hearing in dementia. *Age and Ageing*, 2003, 32, pp. 189-193.



5.3 Carers' support

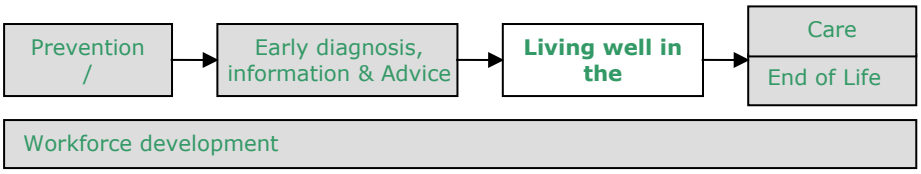
People told us:
* *'I need 'Me time'*
* *'Carers struggle with feelings of guilt'*
* *'Someone keeping in touch'*
* *'Routine medical checks for carers'*
* *'More individualised approach'*
* *'More peer support'*
* *'There can never be enough training'*

Approximately two-thirds of people with dementia live at home and are cared for by family and friends. From literature we know not all caregivers make good use of the available services. Reasons caregivers give for not-using the services are the following[38]:

- managing at the moment
- adequate family support
- denial of need
- invasion of privacy
- do not want interference from others
- fear loss of role
- services refused by recipient of care
- lack of knowledge about eligibility and appropriateness
- inappropriate for needs
- services not available
- inconvenient hours of operation
- concerns about quality of care
- costs
- do not know about services
- lie outside the service system.

From our consultation in July 2009 we learnt that all of these reasons are applicable to people in Stockport. Especially costs, services not meeting needs and the person with dementia refusing any support from somebody else other than their carer, was mentioned often. People told us that they don't often classify themselves as a carer and also do not always know what services are available to them. Luckily a lot of people found the available support and were satisfied with Stockport Dementia Care

[38] Brodaty, H. et al. (2005), 'W*hy caregivers of people with dementia and memory loss don't use* services', International Journal of Geriatric Psychiatry, no. 20, pp. 537-546.



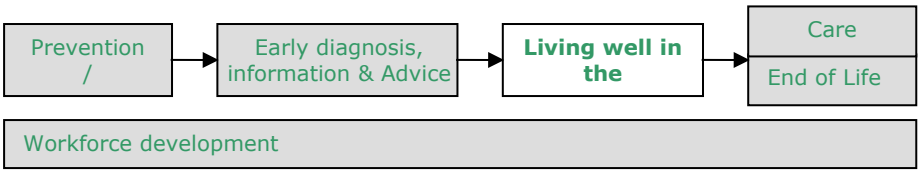
Training and the services the voluntary organisations are providing at the moment.

However, we don't know how many people are not using any service at the moment and there is no clear pathway to access dementia care services and we do not structurally offer carers an assessment of their needs. The role of the GP, but also of the voluntary sector and staff of mainstream services, is crucial in this. An estimated 10% of a practice population is carer and there are probably many more 'hidden' carers.[39] With an early diagnosis and clear signposting to community services people with dementia and their carers could receive information, advice and support the whole way through their 'dementia journey'. It asks for better linking of services and providers informing each other about the available services. Also pro-active role in regularly checking carers' needs is important in combination with providing short breaks to carers to support their important role in caring for someone with dementia.

5.4 Housing support

Evidence in Stockport shows that people with dementia can benefit from the support offered in a variety of mainstream housing, sheltered and Extra care housing opportunities. This will need a joined up approach between health, social care and housing to offer people choice and quality of housing options. Housing and housing-related services can make the difference between a person with dementia continuing to live independently or moving to a care home. Within Stockport we are looking into current and future needs of people with dementia and how these can be met. This will all come together in a separate Older People's Housing Strategy. Also the needs for younger people with dementia and people with learning disabilities need to be taken into account.

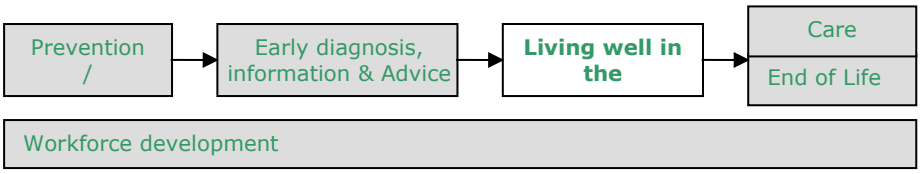
[39] Supporting Carers: an action guide for general practitioners and their teams. The Princess Royal Trust for Carers & Royal College of General Practitioners (2009).



Actions: Living well with dementia in the community

- → Implement dementia advisers to support people in finding the right care and support for them.
- → Create more opportunities for peer support, learn from the three current peer support demonstrator site strands and develop a plan to sustain good practice.
- → More facilities for carers to have a break.
- → Better use of personalised care to support people with dementia and their carers at the place, time and with the staff they want.
- → Implement a pathway for people with dementia and learning disabilities including regular health checks for people with Down's Syndrome.
- → Develop an integrated pathway for people with young onset dementia.
- → Understand the needs of people with dementia and their carers from BME communities and develop support tailored to their needs.
- → Undertake an inventory of staff members, especially within the home care agencies, speaking different languages to provide a better match between demand and provision of care.
- → Ongoing training for mainstream staff, specialist dementia care staff and informal carers, to provide quality care for people with dementia including BME groups, people with sensory impairments, people with learning disabilities and people with young onset dementia.
- → Recognition of the role carers in service provision.
- → Undertake a housing needs analysis and developing specialist and supported housing options accordingly to give people choice and to offer people support to live an independent life as long as possible.

Agreed outcomes in 2015 including performance measurements:



6. Dementia care in general hospitals

People told us:
* *'People discharged in more worse condition'*
* *'Dementia diagnosis should be in the notes'*
* *'Staff not trained to cope with people with dementia'*
* *'Treated disrespectfully'*
* *'Listen to the relatives who know the patients best'*

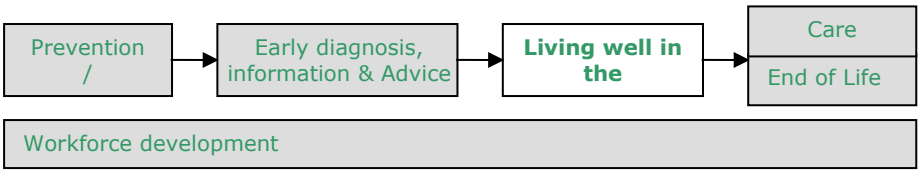
People with dementia sometimes need to be admitted to hospital for treatment of other conditions they might have. Admission to hospital can be stressful and worrying for anyone, but for people with dementia the experience is often devastating. The fact that they may be disorientated in time and place, and thus not able to understand why they are in an unfamiliar environment, leads to fear and anxiety that presents many challenges to staff working with them.

Unfortunately local evidence from the service users and carers' consultation and from Alzheimer's Society's report 'Counting the Cost, caring for people with dementia' (November, 2009) shows that dementia care needs to improve in hospitals. The Alzheimer's Society's report shows that people with dementia have a longer length of stay than others, a hospital stay can have a negative impact on a person with dementia and most of the staff don't feel confident in caring for people with dementia. Both carers participating in the Alzheimer's Society research and in the consultation in Stockport felt that staff in general hospitals were unaware of dementia and not well enough trained to care for people with dementia. A more person centred focus is needed.

As dementia increasingly becomes a co-morbidity of older people admitted to hospital, it is important to create a dementia friendly and non-distracting environment, improve awareness and understanding of dementia by staff, invest in getting to know the patient and communicate effectively and consistently with people with dementia and their carers.

The National Service Framework for Older People[40] aims to provide a collaborative approach, shared care protocol, between GPs and hospital

[40] Department of Health 2001



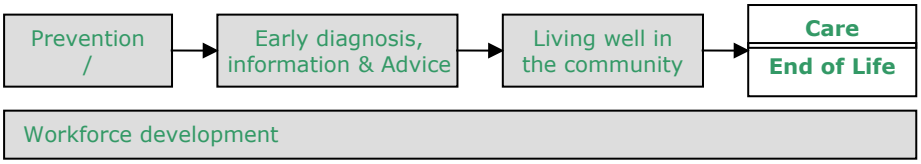
specialists in mental health so that dementia patients receive a more positive experience in general healthcare.

Finally, the focus in dementia care should be on preventing hospital admission, for example by organising quality alternatives in the community such as intermediate care.

Actions: Improving dementia care in general hospitals

- → Improve staff training regarding recognising dementia, caring for and communication with people with dementia and their carers, signposting people to services in the community.
- → Create a dementia friendly environment for people with dementia in hospitals and ensuring carers are recognised as a partner in the care.
- → Implement a mental health or dementia liaison service, bridging the gap between physical and mental health care in hospital, to support ward staff in providing quality care for people with dementia and to organise a smoothly discharge into the community.
- → Reduce the number of transfers and the length of stay during a hospital admission for people with dementia.
- → Ensure enough alternatives in the community, like intermediate care.
- → Recognise the role hospital staff can have in signposting people to appropriate support in the community.
- → Ensure a good hand over when a person is referred to hospital and at discharge from hospital to services in the community to guarantee continuity and a person centred approach.

Agreed outcomes in 2015 including performance measurements:



7. End stage of dementia care: Quality care in care homes and End of Life care

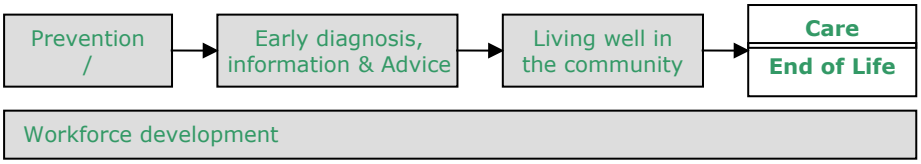
7.1 Care homes

At least two-thirds of all people in care homes have a form of dementia.[41] This figure proves the necessity for every care home to make dementia care an explicit part of their daily service provision to their residents. This means a continuing investment in staff skills and knowledge to deliver quality dementia care focussed on the lived experience of the residents combined with providing a physical environment that enables people to feel at home and move around the home safely. A strong link and involvement in the community can support purposeful activities. And services like day care and respite care offered by a care home can in addition accustom people to a care home and support them to gradually make the step from attending an 'outpatient' service to permanently living in this care home as their dementia progresses.

In general, Stockport aims to only commission services from providers which are CQC-rated as 'Good' or 'Excellent'. Providers are offered support to improve their services and maintain quality of care and focus on dignity in care, e.g. via work force development, leadership programs, contract mechanism, a price premium and organising opportunities to share good practice. We also continuously monitor that our local care home capacity meets the demand in Stockport.

Personalised care should be the starting point in an individual's care plan and care has to be tailored to the strengths, abilities and needs of the person with dementia. The input of carers in the individual care plans is very valuable as they know the person best and often, the relatives want to maintain the relationship with the person with dementia. Every care home should support this.

[41] National Dementia Strategy (2009), pp. 57.



Partnership working resulting in a shared care approach between GPs, Community Mental Health Team and care homes would be the best way forward to ensure residents get the medical and mental treatment they need. A regular review of treatment will be necessary, especially for people who are prescribed anti-psychotic drugs. The National Dementia Strategy promotes the formulation and deployment of non-pharmalogical management strategies for challenging behaviour in dementia and a rapid response of the community mental health team to problems as they occur within homes.[42]

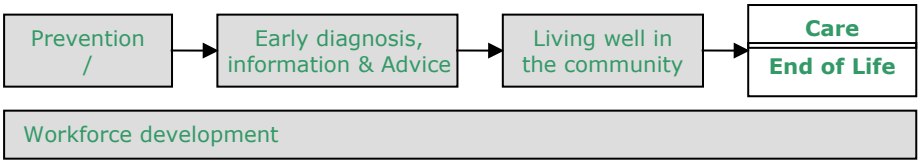
During this stage of dementia special support to families might be needed. An admission to a care home can be a stressful event for family and friends of the person with dementia. Following admission to a care home, family and friends can feel uncertain about their role as to how they now 'fit in' to the life of the person they cared for. People can also experience feelings of isolation or guilt or loss because they don't need to care that intensively for the person with dementia anymore. Services offering advice, training and peer support can assist carers at this stage.

7.2 End of Life Care in the community and in care homes

One aspect in the care of older people which deserves special attention is 'end of life' care for people with dementia. End of life planning needs to start early to ensure the person with dementia has still the capacity to express their wishes. Also involving the family and managing their expectations is part of good quality of end-of-life care.

In Stockport a high proportion of the (care home) population still die in hospital. Most people who die in hospital however, would prefer to die in their own (care) home. With more support services in the community we could better meet people's preferences in their own home or their other preferred place to die.

[42] National Dementia Strategy (2009), pp. 60



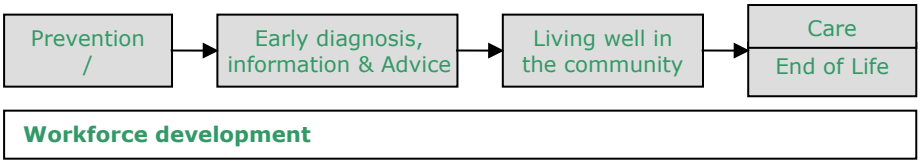
The principles and priorities outlined in the Department of Health's End of Life Strategy (2008) need to apply for people with dementia as well. This includes use of appropriate tools and pathways including preferred priorities of care, Gold Standards Framework and Liverpool Care Pathway for people with dementia. We need to ensure that people in the later stages of dementia are assessed by primary care teams to identify and plan their palliative needs.[43] In addition the national consultation on dementia care stresses the importance of appropriate pain management during the end of life stage.

Actions: Quality dementia care in care homes and End of Life care

- → All care homes have a 'good' or 'excellent' CQC rating
- → Regular staff training in care homes and the introduction of a local leadership development programme focusing on dignity in care, the lived experience of residents and a dementia friendly environment in care homes and specialist housing.
- → Personalised care plans.
- → Support from community mental health team in care homes especially regarding personalised approaches to deal with challenging behaviour.
- → Up to date medication protocol meeting the latest NICE guidelines including regular medication reviews especially with respect to prescription of anti-psychotic drugs.
- → Dementia care incorporated in palliative care plans.
- → Timely discussions about end of life arrangements.
- → Offer specialist and supported housing options to give people choice and to offer people support to live an independent life as long as possible and prevent them to go into a care home unnecessary.

Agreed outcomes in 2015 including performance measurements:

[43] Draft Quality Standards, NICE Clinical Guideline 42 Dementia, November 2009.



8. Workforce development

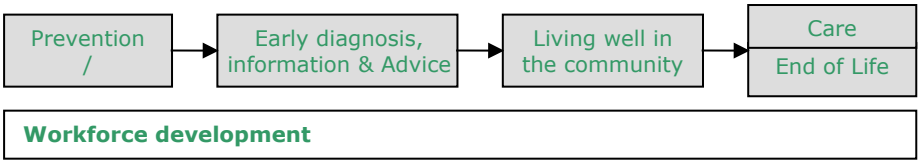
Developing dementia friendly services requires a whole system approach. People with dementia should receive their care from staff that have been trained and are competent in delivering good quality dementia care. In addition the environment, work patterns and procedures need reconfiguring to support the needs of persons with dementia too. This will especially be a role for service managers to address these issues and to create a dementia friendly culture.

Some aspects of staff training can also be beneficial for informal carers. These courses should therefore also be accessible for this group of carers.

As most social care and health staff in Stockport are at some point also in contact with someone with dementia, mainstream staff should also have a basic knowledge of dementia care, to ensure mainstream services can recognise and meet the needs of people with dementia and their carers. Therefore training around dignity in care aspects like understanding dementia, recognising dementia, general attitude and skills, and legal aspects of working with people who may lack capacity, should be an integral part of all staff development programs. This means further building on the already highly valued staff training programs offered by Stockport's Dementia Care Training and Mental Capacity Act officers.

People with dementia and carers can also fulfil an important role in providing training for staff to raise awareness for their needs by sharing their experiences with staff. The recently started EDUCATE-project run by people with early onset dementia could for example support training, service development and service redesign.

All mainstream staff including volunteers in Stockport have a role in raising awareness for dementia and signposting people to the right services and therefore need to know where to be refer people to. A

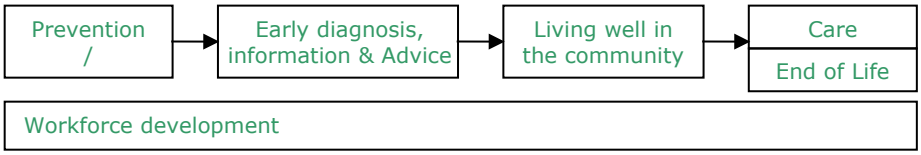


directory of dementia services and other information material can assist them in this signposting role.

Actions: Workforce development

- → Agreed training packages for mainstream staff with regular updates focussing on increasing knowledge, raising awareness and changing culture.
- → Offer a variety of (shared) training opportunities including e-learning in partnership with all providers.
- → Access to courses for informal carers.
- → Involvement of people with dementia in training for staff (e.g. via EDUCATE project)
- → Besides investment in knowledge and skills, also 'change management'-support should be offered to make services more dementia friendly (environment, policies, procedures).
- → Develop a local kite mark for 'high quality' providers offering excellent dementia care and dignity in care.
- → Develop a directory of services to assist staff in their signpost role.

Agreed outcomes in 2015 including performance measurements:



9. Link to other strategies and priorities

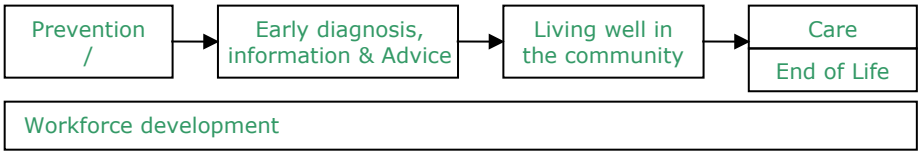
With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness. This asks for a holistic approach. Dementia care cannot be offered in isolation, it needs joined up working between health and social care and a multi-agency approach with voluntary and statutory organisations. One way of implementing this is via our Dementia Champions. We have dementia champions across a variety of teams and organisations. The champions can cascade dementia care information to their colleagues to ensure staff are informed, they can inform each other on new developments and can flag up needs and where improvements are needed in dementia care. The champions are our local ambassadors; ensuring dementia care is and stays on the agenda in Stockport.

9.1 Carers' Strategy

The objectives of Stockport's Carers' Strategy fit in with the objectives of our national and local dementia strategy. Carers of people with dementia need good information, support and care. Besides offering the right facilities for carers also supporting carers to continue or take up work or education is important. Key points are:

- offer a social care system that is flexible, efficient, promotes independence, well-being and dignity and that is inclusive
- prevent crisis situations by focussing on early intervention and regularly need assessments e.g. by GPs and dementia advisers to arrange support matching the actual carer's needs
- offer access to a comprehensive range of respite / short-break services, including emergency support, meeting both the needs for the carer and the person with dementia
- involve carers in design, commissioning and evaluation of services.

The partnership board and carers' strategy group will oversee that the needs of carers for people with dementia are included in policies and implementation plans within health and social care in Stockport.



9.2 Personalisation

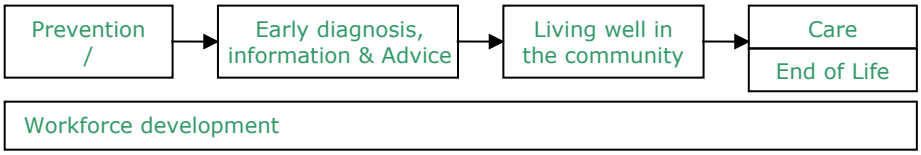
People with dementia and the people who carer for them reported at the local consultation events that they would like to have more flexible support options, at times they want and provided by the care workers they are familiar with.

Within the social care department of Stockport Metropolitan Borough Council a transformation has been taken place to provide a personalised adult social care system which will meet these wishes expressed by people with dementia and their carers.

By 2011, social care wants everyone living in Stockport to be given the opportunity to meet their social care needs in a way that is personal to them and focuses on what helps them to achieve their goals in life. Personalisation means making the support you receive personal to you, with services built around your needs and wants. If people choose, they can have a Personal Budget that will enable them to buy their own care and support and be able to buy services that fit their own specific needs and choices. The changes will give people in Stockport greater control, choice and flexibility in their life.

9.3 Housing Strategy

Stockport's mainstream Housing Strategy focuses on supporting people to live longer in the community. Under the umbrella of this mainstream strategy two other strategies have been developed: the Learning Disability Housing Strategy and the Mental Health Housing Strategy. The needs of Older People will be taken into consideration in the development of a new Older People's Housing Strategy. This strategy will make implicit reference to the dementia strategy and will focus on meeting the current and future needs of people with dementia and their carers in terms of housing and support. The main objective is to offer people choice and quality in housing and assist them to live an independent life for as long as possible in their own home and/or in a specialist housing facility in the community.



9.4 Telecare / Telehealth Strategy

These technologies can support and enable people with dementia to live more independently and longer in their own home. For example, assistive technology and telecare can help to:

- remind the person to take their tablets at the right time
- help locate a lost item
- orientate the person that it is day time or night time
- assist the person to phone a relative or friend using preprogrammed numbers or pictures
- switch on the lights automatically if the person gets up at night time
- alert a carer or monitoring centre that the person needs assistance.

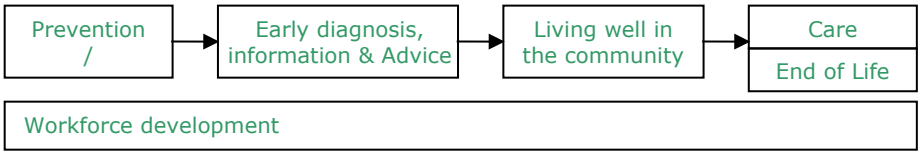
Telecare may also help to support and reassure carers, e.g. it may enable a carer to get a good nights rest, knowing that if the person gets up at night they will be alerted.

9.5 Mental Health Strategy

The Department of Health is currently working towards a shared vision for mental health via their consultation 'New Horizons' (2009). Most of the general mental health key themes like promoting well being & physical health, prevention of isolation, tackling stigma, personalised care, meaningful activity, multi-agency working, innovation and value for money are all themes applicable to dementia care too.

Depression, one of the most common mental disorders in later life, is experienced by people with dementia but also by carers. It is important to be aware that depression and dementia can complicate the condition of people. It is important to relieve the distress and disability resulting from depression by early identification, intervention and treatment.

Improving dementia care needs joint working between medical and mental health care practices to make sure we guarantee a whole person approach meeting the (complex) mix of social, psychological, physical and biological needs of people affected by dementia. Peer support could be a very positive and effective for people with dementia as it empowers, assist people in maintaining their skills and prevents social isolation. It also



gives carers the opportunity to have a break and have some time for themselves.

9.6 Dignity in Care

An overarching principle in dementia care is that all services and support provided in Stockport should be in the interest of the people with dementia and those who care for them. Services have to offer information, care and support in a way people understand and feel valued as individuals.

Another aspect related to dignity, is that the stigma is still very common in dementia. As a result, people with dementia may feel devaluated and unnecessary excluded from mainstream society. Raising awareness and understanding for dementia in society is therefore a very important objective in the coming years.

9.7 Mental Capacity Act and Safeguarding

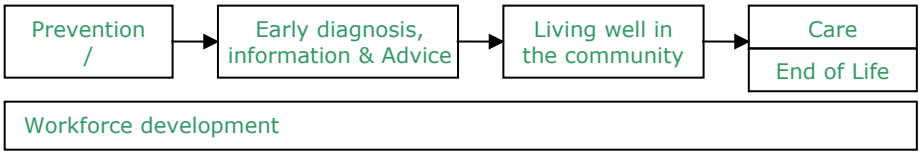
9.7.1 Mental Capacity Act

The Mental Capacity Act provides a clear legal framework for all those working with people who may lack capacity when it comes to making decisions.

Within dementia care three main issues are important when it comes to decision making throughout all stages of the dementia:

- adequate future planning
- supporting people to make decisions
- taking decisions in the 'best interest' of people who lack capacity.

At all times the person's individuality and dignity are paramount within dementia care. It is therefore important to assist people to take advance decisions and organise advance care planning. Raising awareness for this should already be part of the post-diagnostic process. Advice on making an Advanced Decision (to refuse treatment) or making a Lasting Power of Attorney (LPA) that can give someone the authority to make decisions on behalf of the person with dementia when this person lacks capacity, is

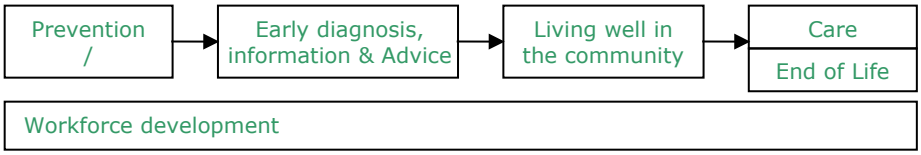


available from the Office of the Public Guardian. Information on these and other relevant sections of the Mental Capacity Act should be made available to people with dementia and their carers.

People have a legal right to make their own decisions as long as they are capable of doing so. This is important, as a diagnosis of dementia does not mean a person lacks capacity. Even as symptoms, mainly in the later stage of the illness, do have an effect on functioning, there will be many decisions a person can still make for themselves. It is the duty of workers in health and social care to support decision making and help a person to understand decisions and where possible make them at the right time for them (this can be particularly important with regard to – for example - medical treatment or changing accommodation). Even if a person cannot make a fully capacitated decision we must still involve them as much as possible and take their views and wishes (past and present) into account.

Where a decision has to be made on someone's behalf then it must be made in that person's 'best interests' and be the least restrictive possible of their freedom. It is therefore important to involve the person or persons who know the person with dementia best. For example a nurse giving an injection, a surgeon considering an operation or a social worker looking at care home options will have to consult with others before making decisions, and that must include family and carers where they are available and willing to be involved.

The Mental Capacity Act sets out how a decision can be made in the best interests of a person if they are not able to make a particular decision for themselves. Mental Capacity Act training programmes are available to all health and social care staff in Stockport, including e-learning packages, and should be a mandatory requirement within each organisation. All relevant staff should be trained and maintain their skills to ensure they understand how to assess capacity and make best interest decisions working to the Mental Capacity Act Code of Practice. The relationship



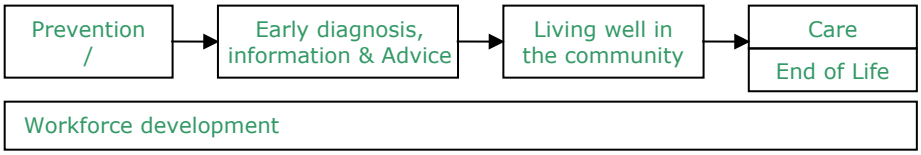
between the Mental Capacity Act and dementia care will be a prominent topic within all training provided. We will also ensure staff will be offered support from specialised staff members in case they come across decision making related to the Mental Capacity Act and want assistance.

9.7.2 Safeguarding and the protection of vulnerable adults

Abuse and neglect of vulnerable adults is one of the most serious and still hidden problems of our society. Just because people are physically frail, or have mental health needs is no excuse for them to be subjected to exploitation or bullying, or to be treated with anything other than respect and dignity at all times and it is our aim to ensure that clients and their families can have confidence in the services provided in health and social care in Stockport.

To this end we have placed dignity in care, safeguarding and the protection of vulnerable adults high on the agenda and we focus in the first instance on prevention. We do this via robust recruitment processes, a comprehensive programme of staff training and by having the right support in place to assist staff in organising the most appropriate care and treatment. In working with people whose capacity to make decisions are limited we are at all times compliant with the Mental Capacity Act (2005) and its Code of Practice when dealing with safeguarding and protection issues

Unfortunately things can go wrong and people (staff, family, carers) sometimes raise concerns regarding abuse and neglect or poor practice that may be suspected or actually happening. In these cases we have ensured that we have joint procedures in place to provide for the timely reporting of these concerns, a thorough investigation of the circumstances and the development of appropriate measures to safeguard people from further harm. Additionally we are committed to learning from these situations and to avoid further incidents in the future. These multi-agency procedures are common to health and social care providers as well as other associated organisations.

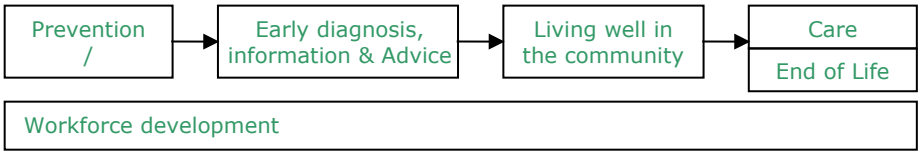


9.8 Older People's Joint Commissioning Strategy

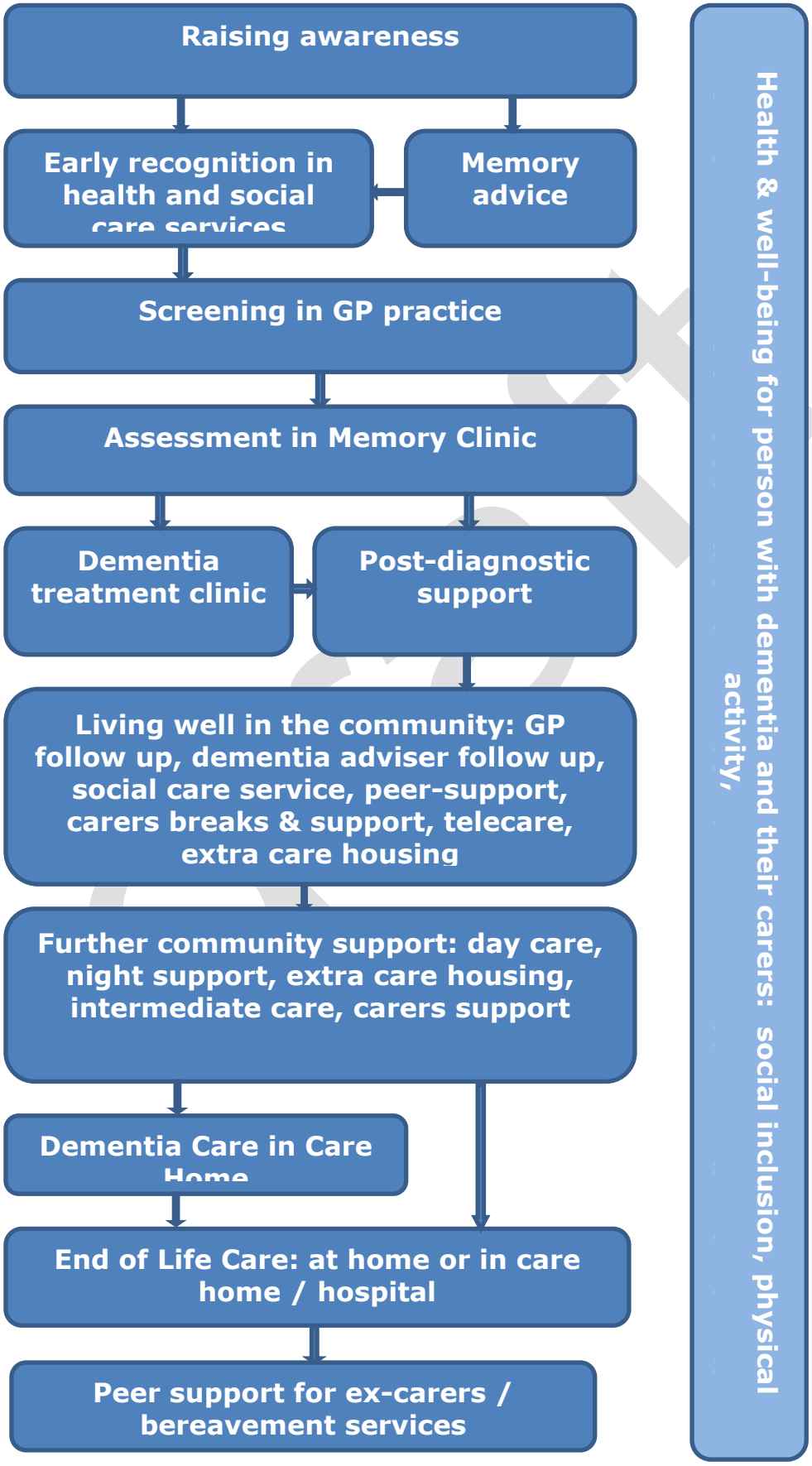
Implementing the objectives of the National and Local strategy will be monitored by the Older People's Joint Commissioning Group and Stockport's Working Group for Older People. We will also make sure links to adult services, housing, learning disabilities and mental health will be in place to monitor progress as well as to the Health and Well-being partnership board.

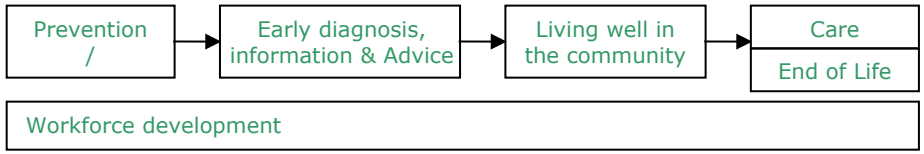
A two-year action plan including targets and performance monitoring will be attached to the local strategy to ensure we make progress in further improving dementia care in Stockport. The implementation of the action plan will be a shared responsibility of all organisations involved in dementia care.

Combining resources, sharing knowledge and maintaining our passion for dementia care will be the way forward.
Together we can make a positive difference to help people to overcome the problems of dementia, to prevent crisis and to improve the quality of life of all involved!



10. Pathway, actions and performance targets





→ Based on the outcomes of the consultation (8th of February till the 8th of March 2010) the final version will also have:

- an implementation plan,
- an overview of the resources needed,
- targets and performance measurements
- who is responsible to do what in the coming years.

This plan will be reviewed every two years. Below you can find a first draft of this plan:

Appendix 1

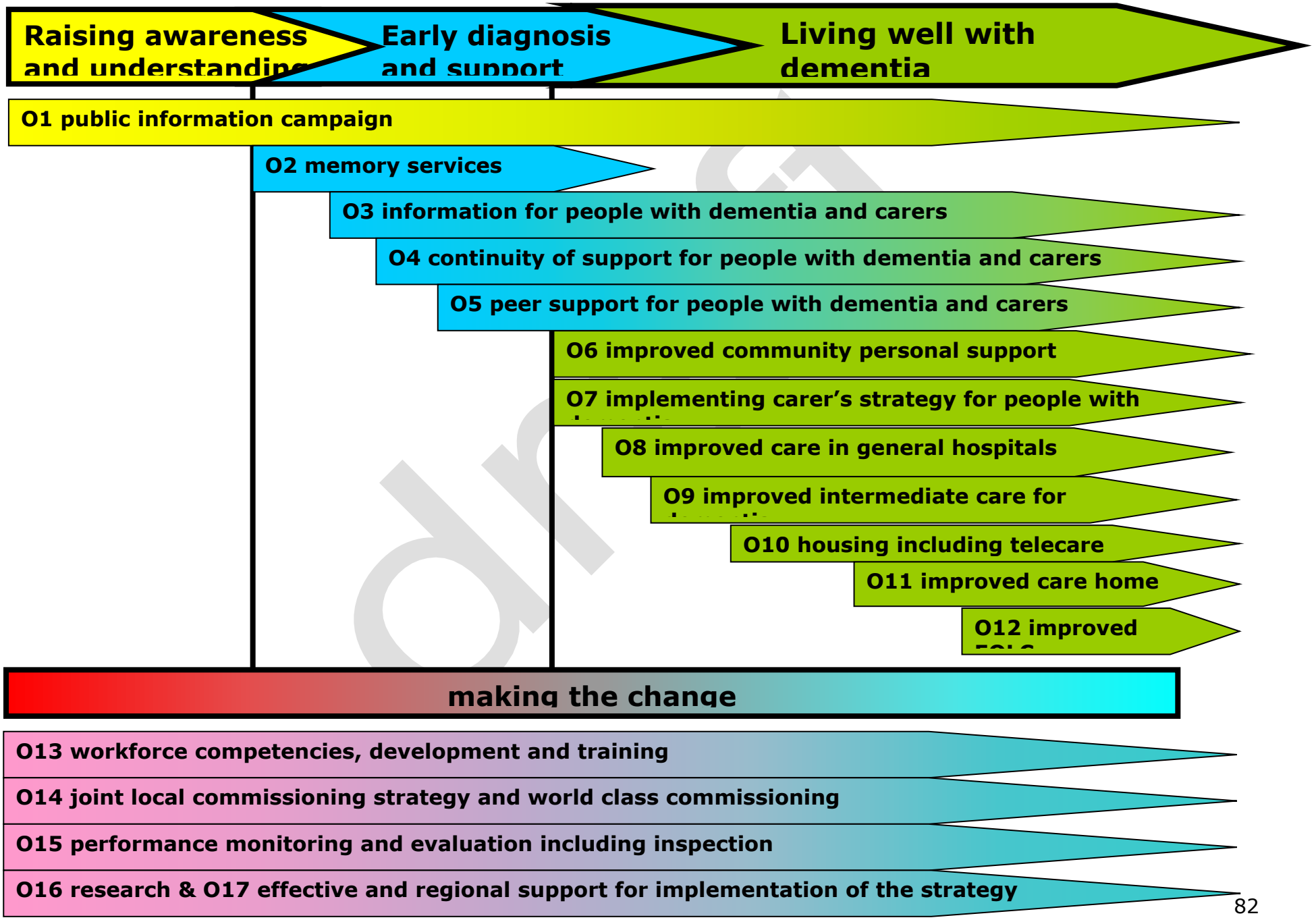
Steps in pathway and measures	Current interventions and service provision	Preferred situation	Redesign actions	Impact of initiatives
Raising awareness •300 health and social care staff (inc vol and independent sector) trained in dementia per annum •Dementia advisors providing advice and support in post	Fragmented services, no clear responsibility for raising awareness and advice people to go to their GP if they worry about their memory	•Joint working between social care, health care and voluntary sector •Advisors attached to voluntary organisation who can to run clinics and provide information and signposting •Training for mainstream staff to be prepared to recognise dementia and signpost people in the right direction	•Developing directory of services and update information materials •Appointing dementia advisors •Staff training to recognise dementia and signpost people in the right direction •Public Health campaign to inform people about dementia, how to recognise it and how to support others with dementia, where to seek help •Special actions needs for BME groups to explain and raise awareness for dementia	•Better informed staff •More support and better access to services for people with dementia •Assisting people during their emotionally difficult stage of getting the diagnoses •More people will go to their GP and people will go earlier to their GP if they worry about their memory •More prevention possible (e.g. vascular dementia, Alzheimer's disease) •Beating the stigma people with dementia experience
Early recognition •Number on QOF register increased from 1500 to 3000 by 2014 •Numbers receiving a diagnosis increase from 500 per year to 750 per year by 2014	In Stockport we are doing better than average on recognising people with dementia in an early stage but still not all people with dementia are on the QOF register or know in the system in an other way.	•Early detection of development of dementia to enable people to prepare for the future •Early referral to secondary care for diagnosis of dementia and type of dementia and start of care plan	•Raising awareness (public and staff) •GP training how to recognise dementia and put in place performance management measures	•More people will go to their GP and people will go earlier to their GP if they worry about their memory •More prevention possible (e.g. vascular dementia, Alzheimer's disease)
Memory advice Memory information and advice services in place Numbers receiving advise to reach 1000 per annum by2014	At the moment we don't have a service in the community where people can drop in and ask for information & advice and which can encourage & support people in getting a diagnosis	•Dementia advisors running clinics in all 4 PBC areas, closely working together with GPs, signposting people with dementia and carers to the right services and who can assist in organising peer support	•Appointing dementia advisors (one in every PBC area) •Stimulate the local vol sector market to be able to provide dementia advice in partnership with other providers	•One port of call •Supporting GPs with their role of signposting and information provision •Up to date information meeting needs of the population •Impact on raising awareness and informing public about dementia

Appendix 1

Steps in pathway and measures	Current interventions and service provision	Preferred situation	Redesign actions	Impact of initiatives
Screening and initial diagnosis by GP •Number on QOF register increased from 1500 to 3000 by 2014 •Screening tool in place for people with LD	•No protocol available what GPs have to do before referring a patient to secondary care Tasks for GPs are: (physical examination, mini mental state score, full bloods)	•Agreed and shared protocol regarding diagnosing people with dementia •Regular health screening for people with learning disabilities (to increase early detection of development of dementia) and other risk groups (stroke, CVD)	•Developing shared pathway •Training of GPs to ensure all GPs are well equipped to follow the guidelines	•Earlier detection of dementia or identifying other medical problems causing memory problems or confusion incl. for people with learning disabilities •Compliance with NICE-guidelines •Equal access to services for all
Assessment in Memory service •90% of patients on dementia medication receive follow up in primary care	•State of the art assessment by consultant and specialist nurse •Patients discharged with care plan •Post-diagnostic support offered to people with dementia and carers	•Continuation of current service provision with earlier discharge to GP and dementia advisor for post-diagnostic support •Better links with primary care and voluntary sector to guarantee follow up in community for people with dementia and carers	•Capacity sufficient to meet current and future demand → increase of capacity and increase in provider contract •Part of post-diagnostic support (information, advice, peer-support can be offered in the community by voluntary sector	•Timely follow up of referral by GP •Properly commissioned memory services
Dementia treatment clinic •Shared care protocol and pathway in place •90% of patients on dementia medication receive follow up in primary care	•At the moment people are treated unnecessary long in secondary care •The current service provision is not specifically commissioned but have been emerged from local and national pressures and priorities	•Secondary care till patient is stable on medication → timely referral back to primary care	•Update of medication protocol •Identify in shared pathway with primary care when patients are ready for discharge back to GP for regular follow up	•Equal access to medication for patients •No unnecessary treatment in secondary care: efficiency •Properly commissioned memory services
Post-diagnostic support •100% of newly diagnosed with dementia receive dementia advisor support by 2014 •All patients and carers able to access dementia training	•Stockport Dementia Care training, Pennine Care and Voluntary sector offering good information and peer-support services but don't meet demand, no services for BME, no equal access, only time-limited services, not pro-actively offered	•Information and support tailored to needs of people with dementia and their carers •Information and support pro-actively offered and meeting the needs of the person with dementia and their carers of that moment •Timely arrangements for end of life arrangements and mental capacity	•Current demonstrator site project will teach us what works best and what services people want •Appointing dementia advisors to coordinate information provision and providing up to date information	•More personalised services •Prevention of burn out for carers •Better use of available resources by joint up working •Dementia advisors can support GPs in their task to regularly follow up patients in the community •Better use of personal budgets

Appendix 1

Steps in pathway and measures	Current interventions and service provision	Preferred situation	Redesign actions	Impact of initiatives
Living well in the community during all stages of the dementia •Hospital liaison service in place •Hospital liaison service identifying and supporting 800 people with dementia per annum by 2014 •Reduction in LOS by 2 days per admission for people with dementia Current carers services increased by 20% •Reduction of care home days by 5%	•At the moment health care, social care, third & and voluntary sector offer good support for people to live well in the community. However not all staff knows well enough how best to provide care to people with dementia, we have some gaps in service provision, not everybody know how to ask for services and therefore wait till crisis situations occur, more carers support needed, services need to be more tailored to needs of persons with dementia and their family	•A specific pathway for people with learning disabilities •More services for people with young onset dementia •Better linked up services across providers •Services more pro-actively offered •Better uptake of service use by BME community •Access for dementia patients to intermediate care •More telecare support •Supporting housing fit for purpose for people with dementia •More carers breaks opportunities •Hospital liaison service	•Training mainstream staff to enable them to provide good quality care to people with dementia especially focus on home care agencies, community health services, social workers and volunteers •Training staff in general hospital and creating more dementia friendly environment •Involvement of EDUCATE project (people with dementia) in redesign •Implementing hospital liaison service following NICE guidance	•More focus on prevention and timely support and less crisis intervention •Shorter length of stay in hospital •Basic quality care for people with dementia and their carers offered by all providers •Better health for carers •Admission to care homes in later state of dementia
Dementia care in Care homes •70% of homes have local kite mark •System for monitoring numbers on anti psychotic meds in place	•Almost all care homes have CQC rating excellent or good but not every home is providing the best dementia care •Not all patients have the right medication	•Increased involvement in day-to-day tasks in care home, more physical activity, more personalised care •Focus on dignity in care •Protocol for anti-psychotic medication	•Developing description of state of the art dementia care and a local kite mark with the care homes in Stockport and measuring all homes against this standard •Medication procedures according to recent research about anti-psychotic drugs	•Increased staff training •Sharing good practice •Medication treatment following actual guidelines
End of Life Care •Dementia end of life pathway in place •Reduced admissions to hospital for EOL dementia patients	•End of life care is mainly focussed on people with other conditions	•Specific support for people with dementia and already addressing end of life arrangement in an early stage	•Stockport's End of life pathway (including gold standard framework and Liverpool pathway) suitable for people with dementia	•Increased demand on end of life care
Peer support for **ex-carers / bereavement support** •Service in place and offered to ex-carers	•Not available at the moment. Ex-carers fall in gap at the moment when their carer role ends	•Support for people who are ex-carers because the person they cared for died or went to a care home	•Assist ex-carers to set up a peer support service for ex-carers	•Preventing social isolation and depressing feelings of ex-carers


Raising awareness and understanding
Early diagnosis and support
Living well with dementia
O1 public information campaign
O2 memory services
O3 information for people with dementia and carers
O4 continuity of support for people with dementia and carers
O5 peer support for people with dementia and carers
O6 improved community personal support
O7 implementing carer's strategy for people with
O8 improved care in general hospitals
O9 improved intermediate care for
O10 housing including telecare
O11 improved care home
O12 improved
making the change
O13 workforce competencies, development and training
O14 joint local commissioning strategy and world class commissioning
O15 performance monitoring and evaluation including inspection
O16 research & O17 effective and regional support for implementation of the strategy

Appendix 2

JSNA report Dementia Stockport

Older People with Dementia

Rationale

- Dementia is the loss - usually gradual - of mental abilities such as thinking, remembering, and reasoning. The most common dementia symptoms include loss of memory, confusion and changes in personality, mood and behaviour.
- Dementia usually affects older people and becomes more common with age. About 6 in 100 of those over the age of 65 will develop some degree of dementia, increasing to about 20 in 100 of those over the age of 85.
- Although most of the people who develop dementia are over the age of 60, it's important to remember that dementia is not a normal part of growing old, and that most older people never develop dementia.
- However given the aging nature of Stockport's population we can expect the numbers of people with dementia to rise.
- The main JSNA analysis showed that **GP practices have diagnosed around 1,500 people with dementia** in Stockport.
- However analysis by the Kings Fund and London School for Economics, on behalf of Alzheimer's Society, suggest that there are around **3,440 people in Stockport** with the condition.

Predicted trends in volumes over time – Age & Gender

Table 1: Trends in people with dementia – Stockport residents aged 65+

Year	Males				Females				Persons			
	64-74	74-84	85+	65+	64-74	74-84	85+	65+	64-74	74-84	85+	65+
2008	272	500	355	1,127	226	956	1,134	2,316	498	1,456	1,489	3,443
2010	279	515	394	1,188	229	970	1,159	2,358	508	1,485	1,553	3,546
2015	305	561	473	1,339	248	989	1,235	2,472	553	1,550	1,708	3,811
2020	336	632	571	1,539	266	1049	1,336	2,651	602	1,681	1,907	4,190
2025	318	714	690	1,722	249	1160	1,512	2,921	567	1,874	2,202	4,643

Source: POPPI

- Currently 3,440 people in Stockport are predicted to have dementia. A third of these people are men, and two-thirds are women.
- Prevalence increases with age, 40% of those with dementia are aged 85 years or more, more than a fifth of the total population in this age group.
- GPs are therefore identifying around two-fifths of those with dementia.
- Assuming that prevalence rates remain the same, if the population changes as expected then by **2015 there are likely to be an additional 400 people** aged 65 and over with the condition and by **2025 there are likely to be an additional 1,200 people**.

Young onset dementia

Figures of the Alzheimer's Society regarding local variations in England gives an indication of at least 73 people between age 30-64 years having

dementia in our borough. This number is expected to increase to 80 in 2021.

Severity of dementia

- National evidence suggests that 55.4% of people aged 65+ with dementia will have a mild form of the disease, 32.1% will have a moderate form and 12.5% will have severe dementia.

Table 2: Estimates of the severity of dementia			
Year	Mild	Moderate	Severe
2008	1,907	1,105	430

Source: POPPI & Dementia UK, Alzheimer's Society

- Applying these estimates to local prevalence we can see that around **400 people in Stockport will have severe dementia and 1,100** will have moderate dementia. It is therefore possible that GPs are identifying patients with moderate and severe forms of the condition, but this hypothesis cannot be tested.
- The proportion of people with severe dementia increases with age, but unfortunately data is not available to allow modelling by age and severity at the local level. It is therefore possible that this figure is an under estimation.
- By 2025, as the population ages, we can therefore expect the number of people with severe dementia to rise significantly, and at a faster rate than the total number of people with dementia rises.

Costs of dementia

- National evidence suggests that people aged 65+ with mild dementia living in the community will on average cost £16,689 a year, those with moderate dementia will cost £25,877 and those with severe dementia will cost £37,473.
- As the severity of dementia increases the proportion of costs born by the informal care sector increases; costs to the NHS are virtually the same for all three groups (around £2,500 per year) while costs to social services rise from £4,935 per year for someone with mild dementia to £7,838 per year for someone with severe dementia, a person with mild dementia costs the informal sector £9,246 a year whilst someone with severe dementia costs £27,096.
- Those people with dementia in supported accommodation cost on average £31,296 per year, however the cost is born by different sectors (usually the family or social services) depending on financial circumstances.

Table 3: Estimated cost of dementia – assuming community based care							
Year	By severity of dementia			TOTAL	Costs born by		
	Mild	Moderate	Severe		NHS	Social Services	Informal Care

Appendix 2

2008	£31,832,966	£28,599,338	£16,127,442	£76,559,746	£8,605,217	£19,622,153	£48,332,376
2010	£32,785,273	£29,454,909	£16,609,907	£78,850,090	£8,862,649	£20,209,165	£49,778,276
2015	£35,235,386	£31,656,136	£17,851,200	£84,742,722	£9,524,973	£21,719,438	£53,498,311
2020	£38,739,508	£34,804,306	£19,626,484	£93,170,298	£10,472,222	£23,879,413	£58,818,663
2025	£42,927,813	£38,567,158	£21,748,392	£103,243,364	£11,604,422	£26,461,126	£65,177,816

Source: POPPI & Dementia UK, Alzheimer's Society

- Applying these estimates to local prevalences we can see that currently **dementia costs around £76.6 million annually**.
- £8.5 million (11.2%) of this is born by the NHS (including primary care, admissions and community care), £19.6 million (25.6%) is born by social services (mainly though day centres) and **£48.3 million (63.1%) is born by the informal care sector**.
- By 2025, if the population changes as expected costs are expected to rise to **£103.2 million** per year.

A note on Residential Care Homes and Dementia

- Older people in residential care homes are much more likely to have dementia than those living in the community, **at all ages and for both sexes more than 60% of those living in these settings are likely to have some form of dementia**.

Geography

Table 4: Estimated numbers with dementia by PBC Locality

PBC Locality	Mild	Moderate	Severe	TOTAL
Bramhall & Cheadle	580	336	131	1,046
Heatons & Tame Valley	402	233	91	725
Marple & Werneth	422	245	95	762
Stepping Hill & Victoria	532	308	120	961

Table 5: Estimated numbers with dementia by ward

PBC Locality	2004 Ward	Mild	Moderate	Severe	TOTAL
Bramhall & Cheadle	Bramhall North	91	53	21	165
	Bramhall South	113	65	25	203
	Cheadle & Gatley	135	78	30	244
	Cheadle Hulme North ^	87	50	20	157
	Cheadle Hulme South	81	47	18	145
	Heald Green	97	56	22	175
Heatons & Tame Valley	Brinnington & Central ^	74	43	17	134
	Heatons North	118	68	27	212
	Heatons South	79	46	18	142
	Reddish North	65	38	15	117
	Reddish South	73	42	17	132
Marple & Werneth	Bredbury & Woodley	90	52	20	162
	Bredbury Green & Romiley	114	66	26	205
	Marple North	101	59	23	183
	Marple South	117	68	26	212
Stepping Hill & Victoria	Davenport & Cale Green	76	44	17	136
	Edgeley & Cheadle Heath	66	38	15	120
	Hazel Grove	109	63	24	196
	Manor	69	40	16	124
	Offerton	82	47	18	147
	Stepping Hill	99	58	22	179

^ note part of this ward is also in Stepping Hill & Victoria

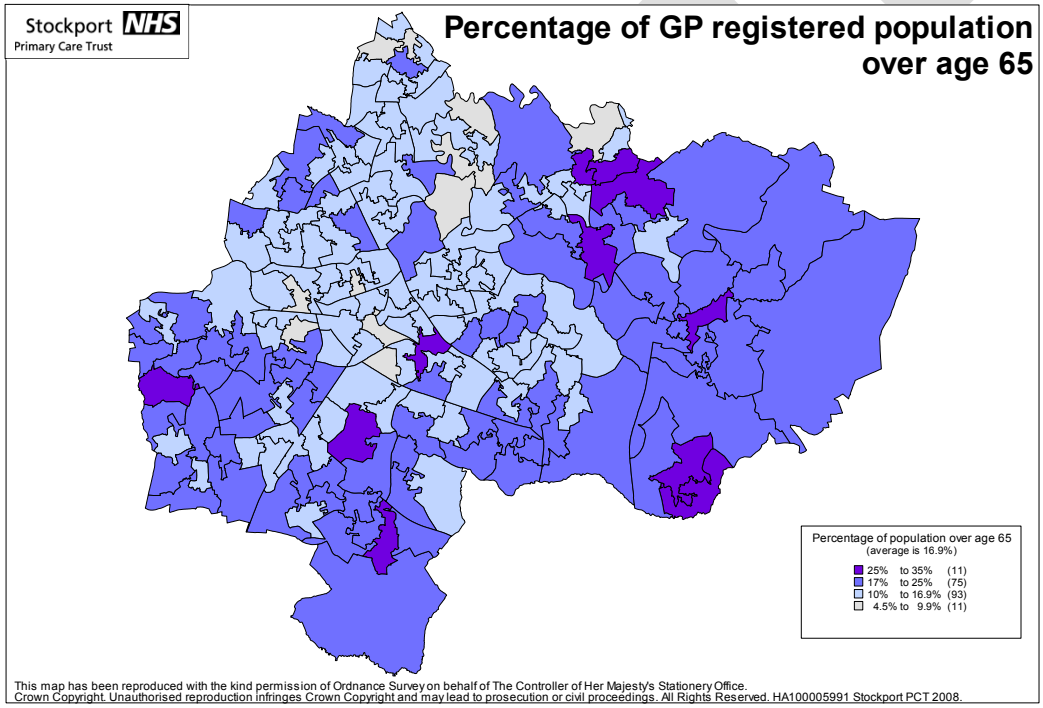
Source: POPPI & Dementia UK, Alzheimer's Society & Exeter Patient Registration System

Appendix 2

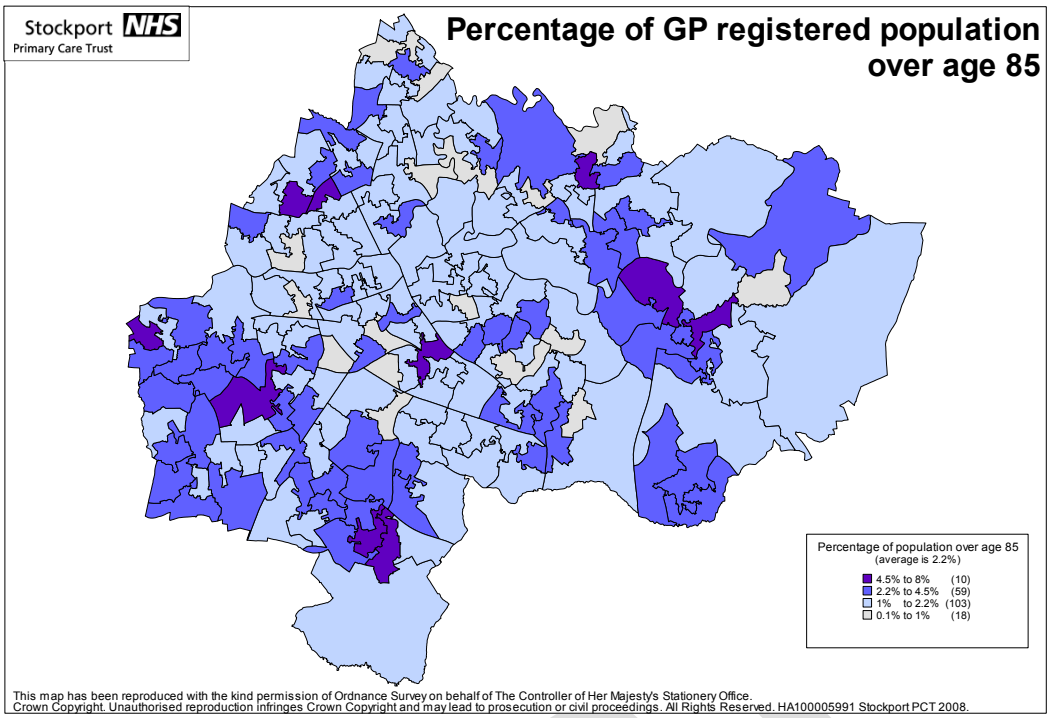
Table 6: 2006/07 Interim QoF prevalence – all ages – GP registered in:					
Numbers on Disease Register	Bramhall & Cheadle	Heatons & Tame Valley	Marple & Werneth	Stepping Hill & Victoria	Stockport
Dementia – Number	333	481	327	301	1,442
Dementia – per 1,000 16+	4.8	7.5	7.2	4.9	6.0

Source: QMAS

- Applying national estimates to local population figures demonstrates how dementia is likely to be distributed across the area.
- The maps on the next page shows how the 65+ and 85+ populations are spread across the borough, until better local data is sourced we can only assume that pattern of dementia will follow the patterns of older populations concentrations.



Appendix 2



Appendix 2

People with Downs's syndrome and dementia

About 20 per cent of people with a learning disability have Down's syndrome, and people with Down's syndrome are at particular risk of developing dementia. Figures from one study (Prasher, 1995) suggest that the following percentages of people with Down's syndrome have dementia:
30-39 years 2 per cent
40-49 years 9.4 per cent
50-59 years 36.1 per cent
60-69 years 54.5 per cent.
Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. However, research has shown that amyloid protein found in these plaques and tangles is linked to a gene on chromosome 21. People with Down's syndrome have an extra copy of chromosome 21, which may explain their increased risk of developing Alzheimer's disease.

Other learning disabilities and dementia

The prevalence of dementia in people with other forms of learning disability is also higher than in the general population. It had previously been thought that the high co-relation only occurred in people with Downs Syndrome but recent research suggests that the following percentages of people with learning disabilities (but not Downs Syndrome) have dementia:
50 years and over: 13 per cent
65 years and over: 22 per cent.
This is about four times higher than in the general population. At present, we do not know why this is the case, and further research is needed. People with learning disabilities are vulnerable to the same risk factors as anyone else. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability may be implicated.

The issues in Stockport regarding learning disabilities

The Stockport Learning Disability partnership works with approximately 720 people with a Learning Disability over the age of 18.
People who are over 35 and have Downs Syndrome are at significantly higher risk of developing dementia and we are aware of 69 people over the age of 35 who have Downs Syndrome in Stockport. The Partnership routinely screens all service users over the age of 65 with a screening tool intended to detect the early stages of dementia.
There are 8 people in supported living tenancies who we believe to be suffering from dementia; they do not all have a formal diagnosis. One of

the issues we face is psychiatric assessment and support as it is unclear whether people with a Learning Disability thought to be suffering with dementia should receive a service from Old age or Learning Disability psychiatry.
There will be other people who have dementia who are living with family carers who will not have come to the attention of the service in relation to a diagnosis. Using the prevalence figures above, there are 61 people between 18 and 39 years of age with Downs Syndrome in Stockport and we would therefore expect 1 person to have a dementia in this age group, 33 people age 40 to 49 years so we would expect just over 3 people to have a diagnosis of dementia, 19 people between the ages of 50 to 59 so we would expect 7 people and of the 6 people aged 60 and over, we would expect 3 people to have a dementia amounting to 14 people.
This is 14 people with Downs Syndrome only; if we consider that 22% of people who are over 65 with a Learning disability may have dementia, this amounts to another 10 people in Stockport that we would expect to have a diagnosis of dementia (from a population of 45 people with a Learning Disability over the age of 65)

Future demand for services for people with a learning disability

It has been estimated that between 2001 and 2011, there will be a 6% increase in the number of people known to services with a Learning disability and a 20% increase in the number of people known to services who are over the age of 60.
Between 2001 and 2021, there will be a 9% increase in the number of people known to services with a Learning disability and 36% increase in the number of people known to services who are over the age of 60.

(source: SMBC)