

NHS Bristol
and
Bristol City Council Health and Social Care

Living Well with Dementia in Bristol
A Joint Commissioning Strategy

2011 – 2015



(Version 26: 01/12/2011)

TRANSLATIONS

If English is not your first language and you need a translation, we can get one for you.

ALBANIAN

Nëse anglishtja nuk është gjuha juaj amtare dhe keni nevojë për një përkthim, ne mund t'ua sigurojmë atë.

BENGALI

ইংরেজী আপনার মাতৃভাষা না হলে এবং আপনার কোন অনুবাদের প্রয়োজন হলে আমরা তা প্রদান করতে সক্ষম।

CHINESE

如果英文不是您的第一語言，而您需要翻譯的話，我們可以為您安排。

GUJARATI

જો તમારી પહેલી ભાષા અંગ્રેજી ન હોય અને તમને ભાષાંતરની જરૂર હોય તો અમે તમને તે આપી શકીએ છીએ.

HINDI

यदि अँग्रेज़ी आप की पहली भाषा नहीं है और आप को अनुवाद की आवश्यकता है तो यह हम आपको प्रदान कर सकते हैं

KURDISH

Heke îngilîzî zimanê we yê yekem nîne û pêwîstîya we bi wergêr heye, em dikarin yekî ji we re bibînin

POLISH

Jeżeli język angielski nie jest Twoim językiem ojczystym i wymagasz tłumaczenia, możemy to zapewnić.

PORTUGUESE

Se o Inglês não é a sua língua materna e precisa de uma tradução, nós podemos obtê-la.

PUNJABI

ਜੇਕਰ ਇੰਗਲਿਸ਼ ਤੁਹਾਡੀ ਪਹਿਲੀ ਭਾਸ਼ਾ ਨਹੀਂ ਅਤੇ ਤੁਹਾਨੂੰ ਦੁਬਾਰਾ ਦੀ ਜ਼ਰੂਰਤ ਹੈ ਤਾਂ ਤੁਹਾਡੇ ਲਈ ਅਸੀਂ ਇਸਦਾ ਪ੍ਰਬੰਧ ਕਰ ਸਕਦੇ ਹਾਂ।

SOMALI

Haddii Ingiriisku aanu ahayn afkaaga kowaad oo aad u baahan tahay turjumaad, annagaa kuu samayn karra.

URDU

اگر انگریزی آپ کی پہلی زبان نہیں ہے اور آپ کو ترجمہ کی ضرورت ہے تو ہم آپ کے لئے فراہم کر سکتے ہیں۔

VIETNAMESE

Nếu quý vị không thạo Anh văn và cần bản dịch, chúng tôi sẽ giúp quý vị một bản.

Contents

Executive Summary	4 – 9
Chapter 1: Introduction	10 – 13
Chapter 2: Strategic Context	14 – 20
Chapter 3: Dementia in Bristol	21 – 29
Chapter 4: Current Dementia Services in Bristol	30 – 34
Chapter 5: Spend on dementia in Bristol	35 – 38
Chapter 6: The future of dementia in Bristol	39 – 46
Chapter 7: Taking forward the Strategy	47 – 51
Appendix 1: Services in Bristol	52 – 60
Appendix 2: Glossary	61 - 62

Executive Summary

Purpose of the Strategy

The purpose of this strategy is to set out the vision for future services for people with dementia and their carers in Bristol, based on an analysis of current and future needs, as well as what people with dementia and their carers have said they would like to see.

Chapter 1: Introduction

This chapter outlines the background to this strategy; what dementia is; and the priorities for future services and experiences for people with dementia and their carers in Bristol.

Dementia describes a syndrome, which can be caused by a number of different illnesses, in which there is progressive decline in several areas of function. Symptoms include: decline in short and long term memory, decline in reasoning and communication and in the ability to carry out daily living tasks.

Following the publication of the National Dementia Strategy in February 2009, a regional review of dementia services in the South West provided the emerging priorities for local action to deliver the National Strategy and the basis for a Bristol strategy.

Population statistics indicate that there will be a significant increase in the number of people with dementia in Bristol over the next 20 years. This local strategy has been developed to ensure that services are put in place to meet the needs of the local population. This strategy is not age specific and covers all people with dementia, including people with learning difficulties and those with early onset dementia.

To ensure that we have the best possible services in Bristol for people with dementia we need to focus on a number of specific areas:

- improve the quality of existing services for people with dementia
- invest money into new and existing services to meet local needs

- shift funding and services to ensure they are appropriately distributed along the care pathway with increased emphasis on prevention and early intervention, as well as increased use of mainstream services
- focus on improving the skills and competencies of all staff who work with people with dementia and their carers
- meet the specific needs of people with dementia and their carers in black and minority ethnic and other 'equalities' communities
- meet the specific needs of people with dementia and learning difficulties and their carers.

It must be noted that this work is taking place in the context of a difficult economic climate and public sector cuts that pose great challenges for all services. There is unlikely to be new funding for dementia services but existing resources need to be used in the most effective way to ensure that people with dementia and their carers are supported from the point of diagnosis. This will mean some redistribution of resources along the care pathway to ensure that the right services are available when people need them. Some services will need to change, for example we expect that increasingly dementia can be managed successfully within 'mainstream' (generic) services rather than being seen as the domain of specialists.

Chapter 2: Strategic Context

This chapter describes key strategies that have influenced and link with this strategy. The strategy is in line with the objectives from “Living Well with Dementia: A National Dementia Strategy” (February 2009), updated in September 2010. The three overarching themes of the original Strategy are:

- Raising Awareness
- Early diagnosis and intervention
- Living well with dementia.

The priorities in the updated plan build on these and are:

- good-quality early diagnosis and intervention for all
- improved quality of care in general hospitals
- living well with dementia in care homes

- reduced use of antipsychotic medication.

More generally, the improvement of community personal support services is integral to and underpins the four priorities as it supports early intervention, prevents people having to go to care homes too early and reduces inappropriate admission to hospital or staying in hospital longer than needed.

The updated strategy also takes account of the plans for reform of the NHS outlined in The NHS White Paper: Equity and Excellence: Liberating the NHS, Department of Health (July 2010).

Chapter 3: Dementia in Bristol

This outlines the current and future level of need in Bristol, including population data and diagnosis rates.

Population estimates of current rates of dementia indicate that there should be between approximately 4000 and 6000 people with dementia. However, only 1907 people are currently listed on GPs registers as having a diagnosis of dementia. The data shows that people are being referred for a diagnosis of dementia, but that we do not know the detail behind this. Data from GP practices shows wide variation in diagnosis rates and further work is needed to improve consistency across the city.

Future estimates of dementia prevalence based on population estimates vary but the latest figures (POPPI 2009) suggest a 23% increase in dementia in Bristol over the next 20 years. Clearly this presents a challenge if resources are to be redirected so that people with dementia and their carers are supported appropriately and sustainably.

As current data about the people who have suspected dementia or who have received a diagnosis is limited, a key task will be to understand in more detail, who is being diagnosed with dementia, and their gender, age and ethnicity. This will enable us to be clearer about which sections of the community are not receiving a diagnosis where we would expect prevalence to be higher and therefore to target services, especially around information and prevention.

Chapter 4: Current Dementia Services in Bristol

This chapter outlines services currently available in Bristol specifically for people with dementia and the number of people accessing them.

In Bristol there are a range of specialist services provided specifically for people with dementia, however many people with dementia are supported within mainstream services, such as home care and residential care.

Specialist services in Bristol include: Day care, residential care, support via voluntary organisations funded by Bristol City Council or NHS Bristol, specialist in-patient care, specialist domiciliary care, mental health liaison services in hospital and community and specialist diagnosis via the Memory Service. In addition some new services have been or are being piloted including Memory Cafes and the Dementia Advisor Service.

The areas where we need to focus most in future is on developing the services for people at risk of developing problems as a result of dementia and where investment in relatively low level services could prevent them needing more specialist services later on - such as peer support. We also need to focus on gaining a clearer understanding of when specialist services such as specialist dementia care in the home, are appropriate and necessary and when mainstream services should be provided. One important theme emerging from the data about provision and usage in Bristol is that the majority of people with dementia receive services provided by mainstream services. These services must be able to meet the needs of people with dementia and therefore, an important part of this strategy is a focus on developing the skills of the workforce providing these services through training and quality assurance, to ensure all services can provide a high quality service to people with dementia. Specialist services will be needed for some people, but for services to be affordable in the long term, these must be targeted at those whose needs cannot be met through a range of skilled mainstream services.

Chapter 5: Spend on dementia in Bristol

In this chapter we look at how much we are currently spending on services for people with dementia and their carers in Bristol

Whilst it is straightforward to identify current spending on specialist services, many mainstream services support people with dementia that makes the overall cost harder to quantify.

We know that we spend a lot of money on a relatively small number of people with very complex needs and that less money is spent on the lower level prevention services, which would support large numbers of people. An over arching theme of the strategy is the need to review current service provision, with the aim of ensuring resources are appropriately distributed along the care pathway with increased emphasis on supporting more people with lower needs. We know that supporting people with dementia and their carers earlier will enable them to keep healthy for longer and more likely to be able to continue living at home.

Chapter 6: The future of dementia in Bristol

This section outlines the short, medium and long-term priorities for making changes to services for people with dementia and their carers in Bristol. Although predictions of future demand vary, we know that we need to increase the availability of services. We also need to change the way services are provided if they are to be affordable, with more emphasis on lower level, preventative services, which may require a shift of resources away from the current focus on specialist services for people with higher levels of need. We also need to improve our understanding of future need by improving collection and analysis of the data about service availability, use and cost.

Chapter 7: Taking forward the Strategy

Consultation

People with dementia, carers, voluntary organisations, clinicians, providers and commissioners were consulted in the development of this Strategy.

Implementation

For each area, a draft work plan has been developed, that sets out priorities, actions, lead names and timescales for delivering each objective.

This Strategy will be delivered by NHS Bristol in partnership, with Bristol City Council. Lead commissioners have been identified by both parties, and leads identified across all the stakeholder groups.

Appendix 1: Services in Bristol

This section provides detail of the current situation of services for people with dementia and their carers in Bristol

Appendix 2: Glossary

Chapter 1: Introduction

This chapter outlines the background to the Strategy, what dementia is and the vision for dementia services in Bristol.

Background to Bristol's Dementia Strategy

Following the publication of the National Dementia Strategy in February 2009, a regional review of dementia services in the south west provided the emerging priorities for local action to deliver the national strategy and the basis for a Bristol strategy. Since then a project board has overseen the development of the strategy and a stakeholder group has contributed to detailed draft plans focused on the identified national and local priorities.

Why do we need a Bristol Dementia Strategy?

Population statistics indicate that there will be a significant increase in the number of people with dementia in Bristol over the next 20 years. This local strategy has been developed to ensure that services are put in place to meet the needs of the local population. This strategy is not age specific and covers all people with dementia, including people with learning disabilities and those with early onset dementia.

What is Dementia?

Dementia describes a syndrome, which can be caused by a number of different illnesses, in which there is progressive decline in many areas of function. Symptoms include: decline in short and long term memory, decline in reasoning and communication and in the ability to carry out daily living tasks. Alongside physical changes, there may be behavioural and psychological symptoms, which include depression, psychosis, disorientation, aggression and 'wandering'.

There are different sub-types of dementia, including: Alzheimer's disease, vascular dementia, mixed Alzheimer's Disease and vascular dementia, Lewy body dementia, dementia in Parkinson's disease, Korsakoff's syndrome (a brain disorder usually associated with heavy alcohol consumption over a long period) and fronto-temporal dementia. (Information from the Alzheimer's Society website www.alzheimers.org.uk)

Dementia can affect anybody, irrespective of age, gender or ethnicity. People who have learning disabilities are particularly at risk of dementia. Although primarily associated with ageing, there is a significant proportion of people who develop forms of dementia at a younger age.

What causes dementia and is it preventable?

There is no single identifiable cause of dementia. For Alzheimer's disease, it is likely that a combination of factors, including age, genetic inheritance, environmental factors, diet and overall general health, are responsible. In some people, the disease may develop silently for many years and symptoms will only appear in response to a specific trigger.

Some types of dementia are more likely to occur if the vascular system is damaged. Triggers include high blood pressure, heart problems, high cholesterol and diabetes; therefore, it is important that these conditions are identified and treated at the earliest opportunity.

The onset and progression of dementia can be delayed to an extent. Lifestyle changes, such as cutting down on alcohol, having a healthy diet and not smoking, can reduce the risk of an individual developing dementia, as well as other diseases.

Bristol's Vision

The underlying principles of this strategy are:

- ◆ To improve the quality of life for people with dementia and their family/carers

- ◆ To ensure all people with dementia are treated with dignity and respect
- ◆ To improve awareness of dementia and promote a message of “healthy ageing”
- ◆ To ensure that the social aspects of living with dementia are captured within our plans and that they are not always driven by a medical model
- ◆ To ensure earlier diagnosis and intervention, with greater support in primary care
- ◆ To ensure that people have the tools to self manage their dementia, but can access support if they require it
- ◆ To have services that are inclusive of all people living with dementia and do not discriminate by on the basis of age, ethnic origin, religion, gender, sexual orientation or disability.
- ◆ That the specific needs relating to the various 'equalities communities' in terms of culture, language, awareness etc. are fully integrated into dementia and mainstream services
- ◆ To have services that are designed to meet the needs of the people who use them
- ◆ To recognise the needs of carers, as well as the important role they play and the expertise they have
- ◆ To make real choice available to service users
- ◆ To take a partnership approach to working with service providers from all sectors to deliver the aims of the strategy
- ◆ To encourage dementia research and to increase patients opportunities to participate in high quality research.

Achieving Bristol’s Vision

To achieve the vision above, we will need to review the patterns and take up of our current services and establish where gaps exist. To ensure that we have the best possible services in Bristol for people with dementia we need to focus on a number of specific areas:

- improve the quality of existing services for people with dementia
- invest money into new and existing services to meet the demographic need
- ensure resources are appropriately distributed along the care pathway with increased emphasis on prevention and early intervention
- focus on improving the skills and competencies of all staff who work with people with dementia and their carers

- address the specific needs of people with dementia and their carers in black and minority ethnic communities and other “equalities” communities
- address the specific needs of people with dementia and a learning difficulty and their carers
- consider the need for dementia research when designing services

Chapter 2: Strategic Context

This chapter will detail how this strategy links with other local and national strategies.

National Policy

In 2009 the National Dementia Strategy was published following widespread consultation. The aim of the national strategy is to ensure that significant improvements are made to dementia services across the UK.

Key messages from the National Dementia Strategy

There are 3 overarching themes:

- ◆ Improved awareness of dementia
- ◆ Earlier diagnosis and intervention
- ◆ Living well with dementia by providing a higher quality of care throughout all services

The themes were then broken down into 17 objectives, 14 of which should be achieved locally and 3 of which are national objectives.

The 14 local objectives are:

- Objective 1: Improved public and professional awareness
- Objective 2: Good quality early diagnosis and intervention for all
- Objective 3: Good-quality information for those with diagnosed dementia and their carers.
- Objective 4: Enabling easy access to care and support
- Objective 5: Structured peer support
- Objective 6: Improved community personal support services
- Objective 7: Implementing the Carers Strategy

- Objective 8: Improved quality of care in general hospitals
- Objective 9: Improved Intermediate Care
- Objective 10: Ensuring housing related services and telecare are available to support people with dementia
- Objective 11: Improved quality of care in care homes for people with dementia
- Objective 12: Improved end of life care
- Objective 13: Informed and effective workforce
- Objective 14: A joined up approach to dementia

The 3 national objectives are:

- Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers
- Objective 16: A clear picture of research evidence and needs
- Objective 17: Effective national and regional support for implementation of the Strategy.

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (Sept 2010).

This updated National Dementia Strategy set out the following priorities building on those in the original strategy:

- good-quality early diagnosis and intervention for all
- improved quality of care in general hospitals
- living well with dementia in care homes
- reduced use of antipsychotic medication.

More generally, the improvement of community personal support services is integral to and underpins the four priorities, as it supports early intervention, prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay.

The updated strategy also takes account of the plans for reform of the NHS outlined in The NHS White Paper: Equity and Excellence: Liberating the NHS, Department of Health (July 2010).

Other important national policy

Everybody's Business 2005

This looked at older people's mental health and contained a service development guide. There are 5 key messages, which remain relevant to the development of future dementia services:

- Access to mental health services should be based on need not age
- Older people's mental health is everybody's business
- Older people need holistic care in mainstream services
- Workforce development is central to driving service improvement
- Whole system commissioning and leadership are vital to deliver a comprehensive service.

Putting People First – A shared vision and commitment to the transformation of Adult Social Care, 2007.

This policy recognises the importance of early intervention and timely support in order to maintain people's independence. Choice and control for individuals is a key theme, which is also reflected in the National Dementia Strategy.

Main principles that will underpin the creation of personalised services are:

- Independence
- Choice and control
- Care closer to home
- Positive experiences for service users/patients
- Improved support for carers
- More joined up services between Primary Care Trusts and Local Authorities

Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own 2008

This strategy sets out the long and short-term vision for the support of carers. There is a joint local carers strategy across Health and Social Care, Children and Young People's Services and NHS Bristol to deliver the national strategy in Bristol. The National Dementia Strategy makes significant reference to ensuring that there are strong links between it and the National Carers Strategy.

National End of Life Care Strategy 2008

The aim of this strategy is to provide high quality end of life care for all adults approaching end of life, giving them the choice of where to live and die. The Bristol Dementia Strategy will be interlinked with the Bristol End of Life Strategy.

Valuing People Now 2009

This is a three-year strategy for people with learning difficulties which addresses what people have said about the support people with learning difficulties and their families need.

NICE / SCIE clinical guidelines, including commissioning a memory assessment service for the early identification and care of people with dementia, 2006

Key recommendations include:

- accurately identifying and referring all people who present with signs and symptoms of possible early dementia
- integrated working provision of memory assessment service
- ensuring that appropriate referral pathways are in place
- providing comprehensive assessment and diagnosis of dementia, including subtype diagnosis
- an integrated approach to care coordination and implementation across all agencies involved in the treatment and care of people with dementia and support of their carers
- providing a quality assured service

These guidelines will be reflected in the detailed work plans that look at the memory service.

NICE Quality Standard for Dementia, 2010

Launched in June 2010, the Quality Standard provides a reference point for service development and there are close links with this strategy. It provides specific, concise quality statements and measures to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. It builds on the 2006 NICE/SCIE guideline above.

The use of antipsychotic medication for people with dementia: Time for action 2009

In this report there are 11 recommendations that will, if implemented, reduce the use of these drugs to the level where benefit will outweigh risk and where it can be assured that patients are being managed safely and effectively. This area is largely seen as being the 18th objective of the National Dementia Strategy.

Local Policy

Quality of Life for Older People Strategy, 2007

Bristol City Council and partners across the city developed the strategy using the Joint Strategic Needs Assessment and a Pensioners' Charter produced by Bristol Older People's Forum. The strategy takes the council's definition of an older person and covers people aged 50+ years. It contains a wide range of targets and has led to direct improvements in services and to the implementation of a range of projects that are co-produced with older people. The strategy has been revised for 2010 having achieved a significant number of its original targets (for 2007-2010).

The plan covers a number of key areas including:

- Hearing the voice of older people
- Challenging perceptions
- Making a positive contribution
- Prevention and early intervention

- Improved health and independence
- Promoting freedom from discrimination

Bristol's Mental Health Services: A Vision for the Future, 2008

This is a 5-year vision for adult mental health services in Bristol, with a commitment to offer service users a real choice in the support and services offered in Bristol.

Putting People First in Bristol

This programme ran from 2008 and ended in April 2011. It was Bristol's local response to a national requirement for all councils to transform social care for adults and develop more personalised services. Transforming services will help the council to respond to a projected increase in demand for services due to demographic changes and also to give people more choice and control over the support they are entitled to receive.

The aims of the programme were to shift the focus from crisis intervention to prevention and to give people, who are eligible for services, more choice and control over their support. The work also included developing universal services such as improved advice and information and building capacity within local communities to support local people outside statutory services.

Health & Social Care Transformation Programme

This programme continues the work begun by Putting People First Bristol and involves a major review of Health & Social Care to make the changes set out above. The programme covers 3 areas: Choice & Control, Commissioning and In House Services. As part of the programme a community engagement exercise will take place to consult with local people about these changes and the priorities for targeting resources over the next 12 months April 2011- March 2012. In October 2010 it was agreed at the council's cabinet meeting that future development of the council's home care service will focus on supporting people with dementia in their own homes, as well as working closely with rehabilitation and reablement services to help people regain and retain their independence.

Modernising Mental Health Services, 2011

In 2011 NHS Bristol undertook a listening exercise to understand the views of all stakeholders in relation to Mental Health Services provided in Bristol. We will need to ensure that services for people with dementia sit appropriately within the findings and outcomes of this work.

Chapter 3: Dementia in Bristol

This next section looks at the data available on the current and future population of Bristol, the number of people being diagnosed with dementia and who these people are.

Bristol population

It is difficult to accurately estimate the number of people we expect to have dementia in Bristol, as this is based on population estimates and expected prevalence of dementia. However we do know what our current population is, how many people we know have a diagnosis of dementia and what the different population estimates predict should be the true number of people with dementia in Bristol.

Nationally it is predicted that there will be a 33% increase in the number of people with dementia by 2025. 2008 POPPI statistics indicated that Bristol should expect a 13% increase by 2025, however this was revised in the 2009 POPPI statistics to suggest a 23% increase in the number of people with dementia. This demonstrates the difficulty of obtaining accurate projections, but it is safe to say that a significant number of people will be affected, and currently all statistics point to increasing figures.

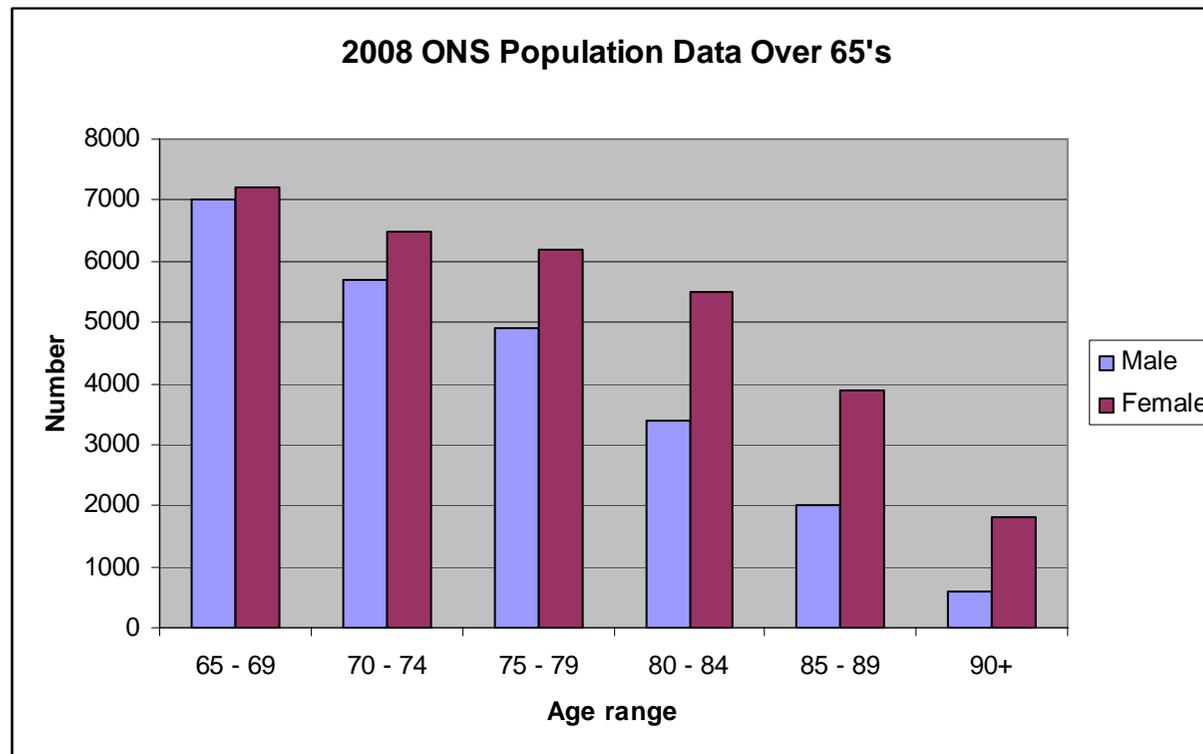
Bristol population data	
Bristol population (ONS 2008)	421,300
Bristol GP practice population (2009)	440,000
Number of people over 65 (ONS 2008)	54,700 (13% of population)
Number of males over 65 (ONS 2008)	23,600 (43% of population)
Number of females over 65 (ONS 2008)	31,100 (57% of population)
Number of people with a Learning Disability	8,328 (2,100 moderate to severe learning disability) People with Down's Syndrome (15-20%) = 1,249 approx.
Number of Black and Minority Ethnic people (2006)	46,100 (11.2% of pop)
Number of Black and Minority Ethnic people over 60 female/65 male (ONS 2007)	4,800 (7.5% of older people population)
Number of people listed in GP practices as having a diagnosis of dementia	1573 in 2008/09 1767 in 2009/10 1907 in 2010/11
Indicative prevalence of people with dementia in Bristol (taken from JSNA 2008)	5921
Indicative prevalence of people with dementia in Bristol (taken from POPPI 2008)	4105

Key

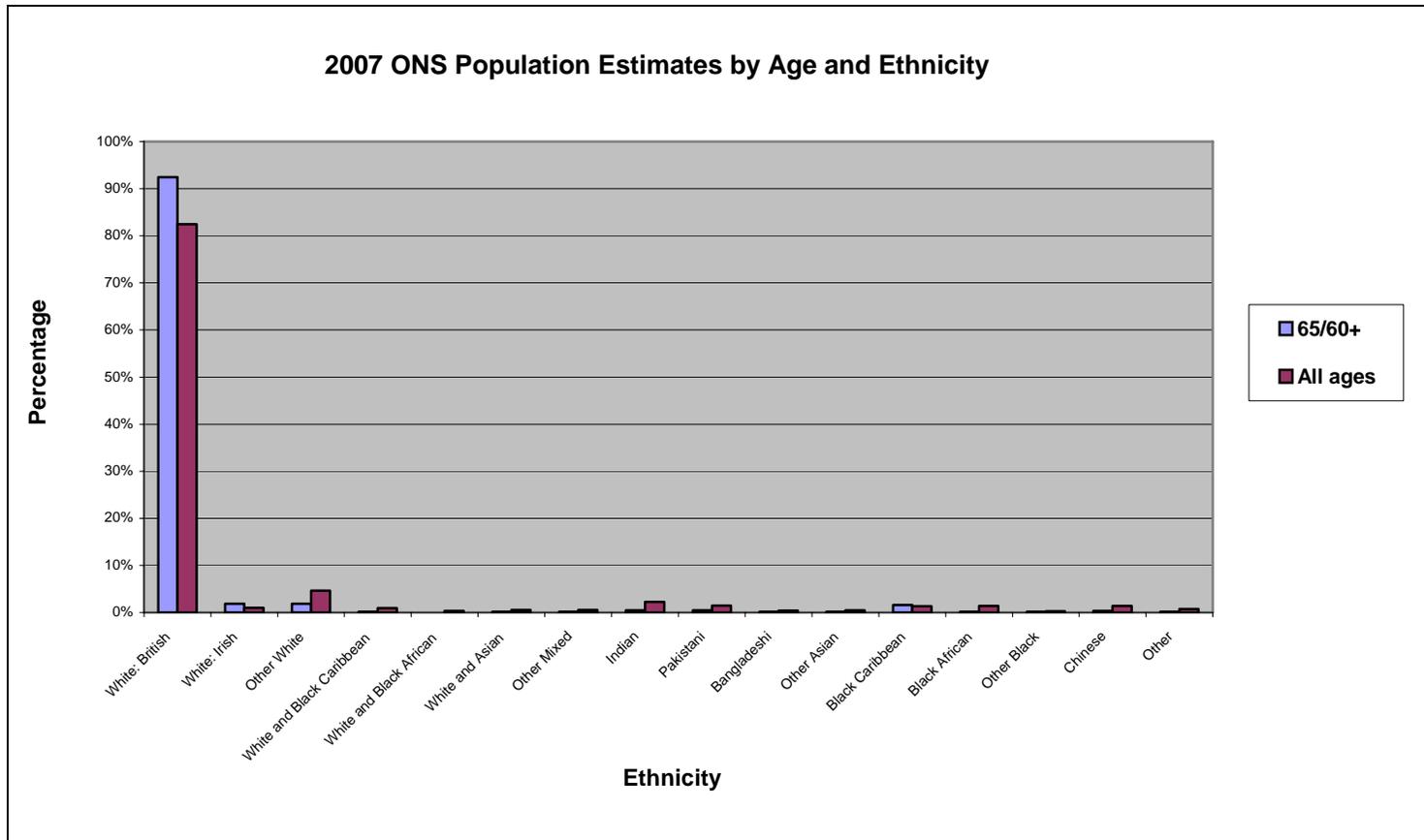
ONS – Office for National Statistics

POPPI – Projecting Older People Population Information System

JSNA – Joint Strategic Needs Assessment



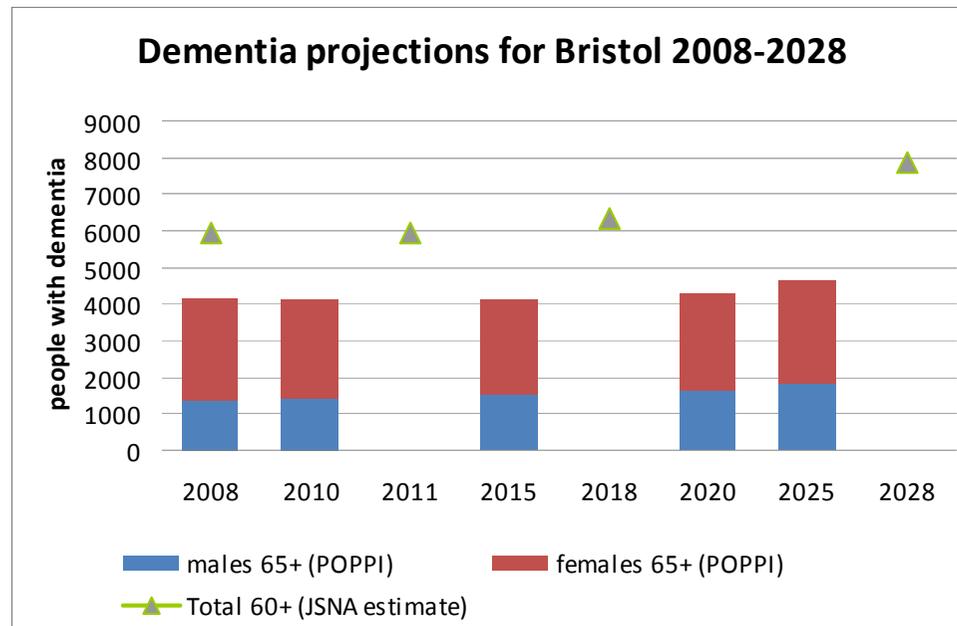
This graph represents the over 65's population in Bristol. (Source ONS 2008)



This graph illustrates the difference in ethnicity between people aged over 60 and the general population. This data shows that there are approximately 10% more people with 'White British' origins in the retirement population compared to the under 60's population.

We expect that, based on the population in Bristol, we should have between 4105 and 5921 people with dementia. However we know that we only have 1907 people currently listed as having a diagnosis of dementia (in 2010/11).

The Bristol Joint Strategic Needs Assessment (JSNA) has estimated a figure for Bristol in 2008 of 5,921 people with dementia aged 60 and over (using ONS 2006 projected age profile for the city.) Using this method we can estimate the numbers of people with dementia in Bristol for 2011, 2018 and 2028 (see graph below), which shows a 33% increase in the next 20 years. This is shown by the green triangles in the chart below. The bars represent the 2008 POPPI predictions of the number of people with dementia in Bristol, showing a 13% increase. This has since been revised in 2009 to a 23% increase.



Clearly the uncertainty of some of the population predictions makes it difficult to plan accurately. Part of the ongoing development of the Dementia Strategy will need to include monitoring and improvements in data analysis to improve the accuracy of the needs analysis. However, there is a clear upward trend in the numbers of older people and those likely to be affected by dementia.

Who currently has a diagnosis of dementia?

The information below provides a snapshot about the people in Bristol who have had a diagnosis of dementia, between April 2010 and March 2011. This information is based on people who have had a diagnosis from the Memory Service, which is the main service people are referred to if they have suspected dementia. However by comparing the figures from GP registers with numbers diagnosed by the Memory Service, we can tell that some GPs and community mental health teams must also be diagnosing people with dementia.

Summary of people with suspected dementia in 2010 – 2011

Category	Number	Percentage of number referred
Number of people referred for a diagnosis of dementia	655 (440 2009-10)	
Number of people assessed for dementia	540 (399 2009-10)	82% (77% 2009-10)
Number of people who received a diagnosis of dementia	47 (71 2009-10)	7% (16.3% 2009-10)

	Percentage
Percentage of Males referred to the memory service	35%
Percentage of Females referred to the memory service	65%
People from Black Minority or Ethnic background referred to the memory service	16%
Percentage of people referred to the service aged 36-65	9%
Percentage of people referred to the service aged 65 years and over	91%

Source: Memory Service (provided by Avon and Wiltshire Mental Health NHS Partnership Trust)

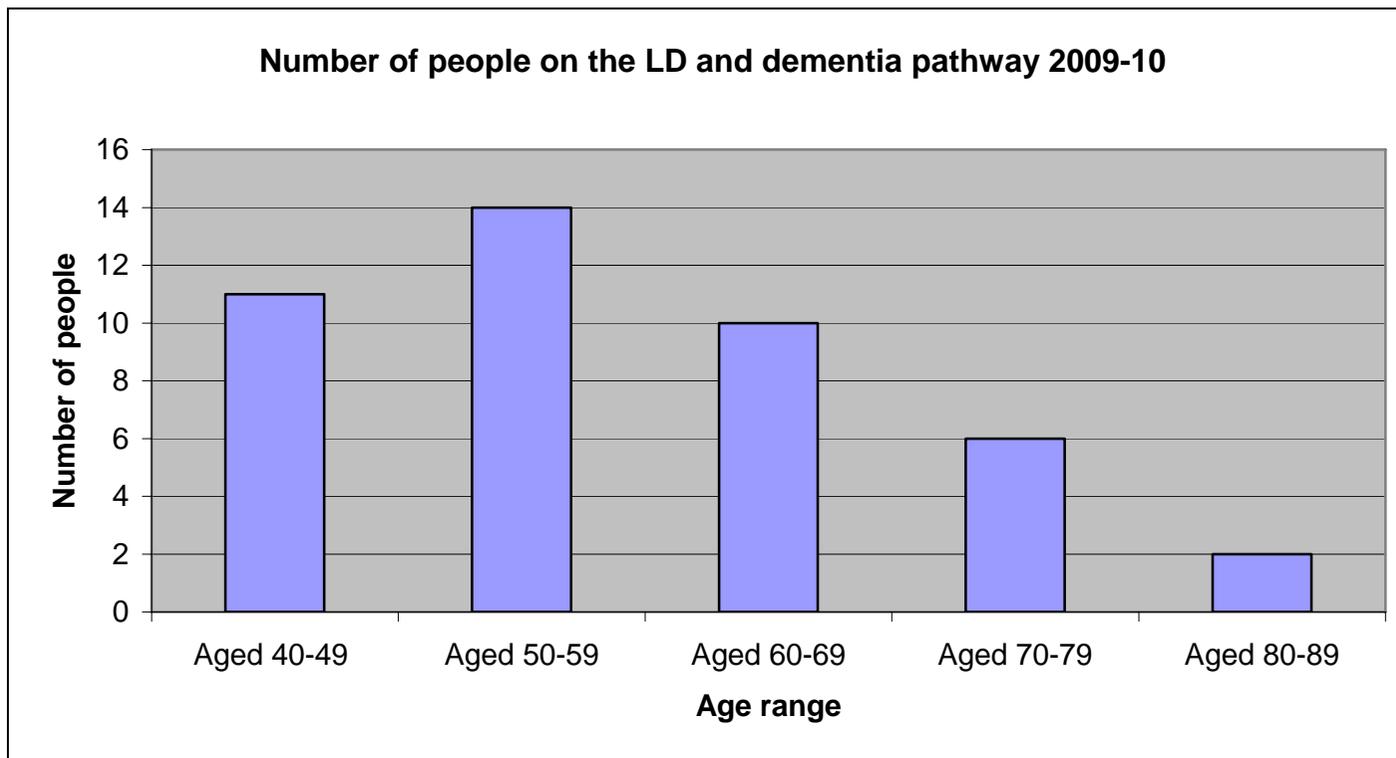
We have a good understanding of who is being referred to the memory service; however we still have limited knowledge about the people who receive a diagnosis of dementia. A key future task will be to understand in more detail, who is being diagnosed with dementia, including their gender, age, ethnicity and which GP practice the referrals are coming from. This will enable us to be clearer about which sections of the community are not receiving a diagnosis, and to enable us to focus our work appropriately, particularly around information and prevention. Of particular significance is the low proportion of those referred who receive a diagnosis.

GP's referring people for a diagnosis of dementia

GP practices are required to keep an up to date register of the number of people in their practice who have a diagnosis of dementia. These lists vary to a great extent with some practices having far higher numbers of people with dementia than expected for their area and others having much lower numbers. Although prevalence of dementia is likely to vary across different areas of the city, this indicates that some GP practices are more likely than others to pick up the need for a referral for diagnosis, which would limit the access of some people to support services. We will use the information behind this to work with GP practices to improve consistency across Bristol. We will need to understand the reason for these differences and work with specific GP practices to ensure that they are aware of how to refer people for a diagnosis of dementia and the benefits of early diagnosis.

Learning difficulties and dementia

In Bristol, people with a learning difficulty and dementia are referred for diagnosis within the multi-disciplinary community learning difficulty teams. A specific care pathway has been devised for people with learning difficulties and dementia and there are currently 43 people on the pathway, 19 of whom already have a diagnosis of dementia. Of the 43 people 53% are male and 47% are female. The age data is set out below:



What this data tells us

This data demonstrates that people are being referred for a diagnosis of dementia. The NICE memory assessment services commissioning and benchmarking tool (NICE, December 2007) enables the commissioner to calculate the relevant activity to be commissioned based on the population for the locality and the indicative benchmark rate. The guidance refers to the average number of people requiring referral to a memory service as 19 per year based on an average practice list size of 10,000 or 0.19% of the full list (or 0.91% of the list aged 60 years and over). This would give us a figure of 800 based on total list size, or 543 based on the over 65 population, which is likely to be the more accurate figure. In 2009-10, 440 people were referred across Bristol, lower than expected numbers. However in 2010-11 655 people were referred, more inline with the expected prevalence. However of this 655 people, only 47 went on to receive a diagnosis therefore further work is required to understand this reasons behind this.

Where are the gaps in the data collection?

We can see there are considerable gaps in our knowledge of who is being diagnosed with dementia. A key task will be working to understand more about the people who are being diagnosed with dementia. What age, gender and ethnicity they are, will be central to this. There are also some areas that are not routinely captured at all, such as sexual orientation. This will be reviewed within an Equalities Impact Assessment. We are very mindful that these factors will crucially affect referrals, engagement with services, acceptance of or understanding of dementia-related symptoms, trust in the competency and inclusivity of services. We need to be able to predict the different levels of demand along the dementia pathway..

How can we address this issue?

We will develop a specification for the memory services that meets our data requirements and we will work with providers to ensure this is collected. We will review all our systems of data recording, to ensure that they are used accurately. This will include detailed reviewing of the register of people with a diagnosis of dementia held by GP practices. We will then be in a better position to anticipate and develop models of potential future demand from our data.

Chapter 4: Dementia Services in Bristol

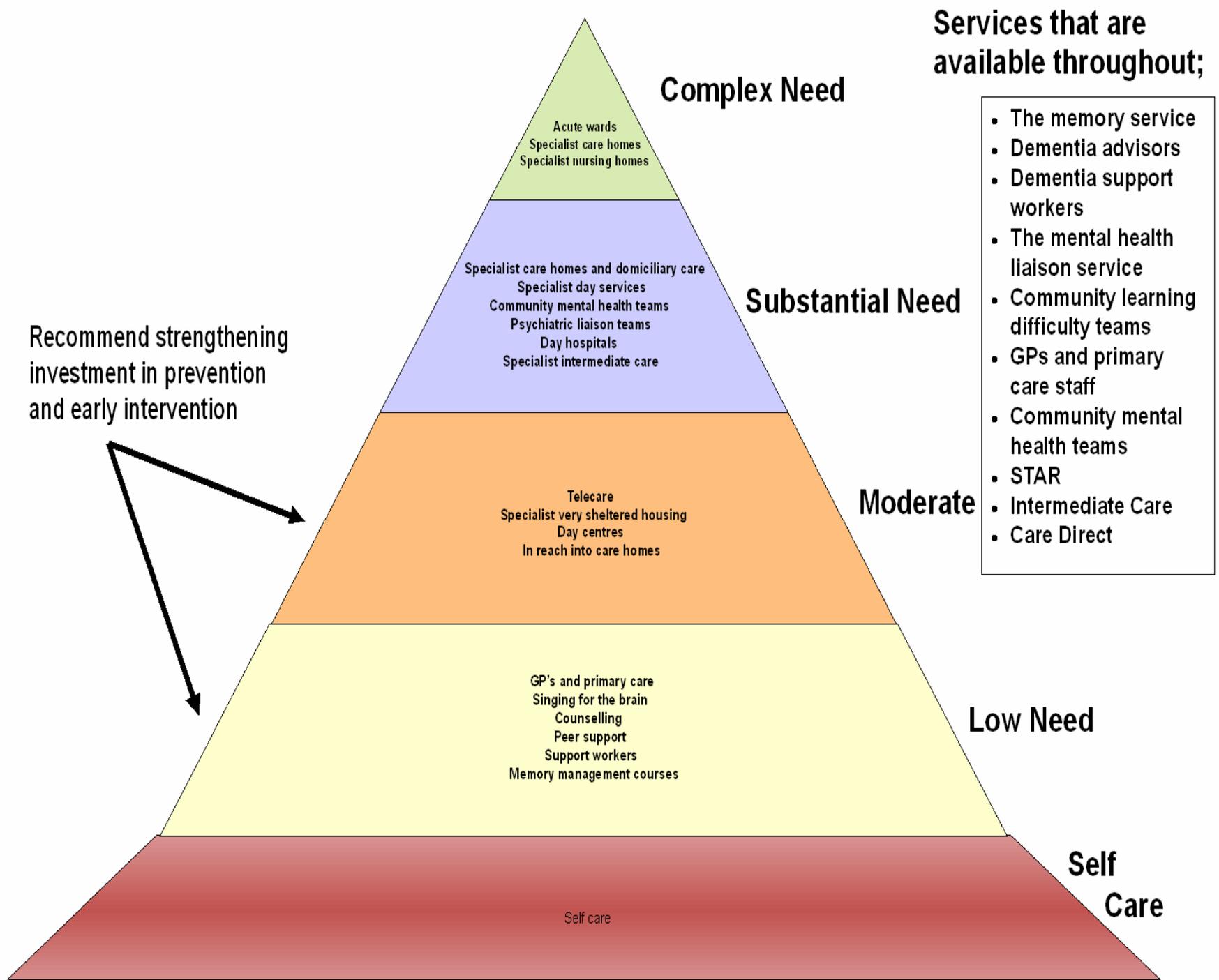
In this chapter we will focus on what services are currently available and how the services are used.

What services do we have in Bristol and who uses them?

In the appendix we have listed all services currently available to people with dementia and their carers. Some services are specialist services provided specifically for people with dementia; however many people with dementia are supported within mainstream services such as home care and residential care.

Specialist services in Bristol include: day care, residential care, support via voluntary organisations funded by Bristol City Council or NHS Bristol, specialist in-patient care, specialist domiciliary care, mental health liaison services between hospital and community services and specialist diagnosis via the Memory Service. In addition some new services have been or are being piloted including memory cafes and the Dementia Advisor Service.

The diagram below demonstrates where the different types of services sit in relation to the needs of the people that they are supporting. The areas where we need to focus most is on developing the services at the bottom of the triangle, which should be aimed at the large numbers of people who are at risk of developing problems as a result of dementia and where investment in relatively low level services could prevent them needing more specialist services later on.



How many people use our services?

As a result of the work undertaken on this strategy we know that we need to improve the data we hold about those who access services in Bristol. Where data is available we have listed the information below, this is for April 2009 – March 2011. It is important to note that these are our specialist services for people with dementia; many more people with dementia access our mainstream services.

Service	Numbers using service April 2009 - March 2010	Numbers using service April 2010 - March 2011	Comments	Level of Need
Dementia Advisors/Support Workers (5 across Bristol)	150	600 (people with dementia and carers)	Figures increased as service embedded.	Self care to complex
Older People's Community Mental Health Team	n/k	1198 referred, 947 assessed	Not all people who are assessed receive treatment, 167 people were assessed and discharged.	Substantial and complex
Older Peoples Hospital Liaison Service (all Bristol hospitals)	n/k	577 referred, 239 assessed	Not all people who are assessed receive treatment.	Substantial and complex
Memory Service	440 referred, 399 assessed	793 referrals 649 assessed	Not all people who are assessed receive a diagnosis of dementia..	Low to complex need
Peer support services (includes those funded by NHS Bristol /Bristol City Council and from	200	250 (estimate)	Includes Memory Cafes, Singing for the Brain, Drop in sessions.	Low

other sources)				
Specialist dementia beds (for people with complex dementia, within a home specifically aimed at meeting the needs of people with dementia)	55 (beds)	55 (beds)	This is number of beds in specialist dementia care homes purchased by NHS Bristol on a block contract.	Complex
	200	250	Estimated number of spot-purchased beds for people with dementia in care homes with nursing.	
	400	548	Number of beds purchased in specialist care homes by Bristol City Council	
	150	57 (capacity = 83)	Number of specialist beds in care homes run by Bristol City Council.	
Specialist dementia domiciliary care	10 people per week (54 hours)	20 (158.75 hours)	Purchased by Bristol City Council.	Substantial and complex

What does this information tell us?

From the above we can see there are some gaps in our data about how services are being used. We also need to collect more qualitative information about the effectiveness of services in relation to their cost, the impact of the services received on individuals and their carers and more detailed information about service demand such as waiting lists. Filling the gaps in our data is a priority in developing and delivering this strategy.

The information in the table shows that there are a number of services available for substantial and complex need. Conversely there is limited provision for people with low and moderate need.

Changing the direction of care

Many of the messages in current national strategies are about helping more people to live at home with support for as long as possible. It is clear from comparison with other areas of the country that in Bristol too many people are admitted to hospital or a care home where their care could be managed in other settings. We are committed to developing the provision of intermediate care and reablement services to enable more people to receive short term care and support at home for short term crises due to health or social care needs.

In order to support more people at home we need to develop a range of services at different levels, some of which will be new, others will build on existing services.

New services are likely to include preventative services such as peer support services. Some existing services will be reshaped, for example the Bristol City Council Home Care service will be developed into a short term specialist dementia service aimed at reablement. The aim of this service is to help people with dementia stay at home where possible by providing rapidly accessible support to support them, their carers and home care agencies. For some people ongoing specialist home care may be appropriate but this is likely to be the minority. The majority will be supported by generic home care agencies but we recognise the need to work with these to develop the skills of the workforce through training and raising awareness of dementia.

Chapter 5: Spend on dementia in Bristol

This next chapter looks at what we are spending on specialist dementia service.

What do we spend on services at the moment?

Whilst it is relatively straightforward to identify current spending on specialist services, many mainstream services support people with dementia which makes the cost harder to quantify. For example GPs, Intermediate Care, Occupational Therapists, and Social Workers all provide services to people with dementia and their carers. . In this section we capture what is spent on “specialist” dementia services, but this does not therefore include all services accessed by people with dementia and/or their carers. It must be noted is not possible to separate from within the funding streams, what percentage of the funding is for people with dementia and what is for other mental health conditions for older adults.

We know that we spend a lot of money on a relatively small number of people with very complex needs and that less money is spend on the lower level prevention services, which would support large numbers of people. An over arching theme of the strategy is the need to review current service provision, with the aim of ensuring resources and funding are appropriately distributed along the care pathway, with a focus on prevention and early intervention, to support more people with lower needs. We know that supporting people with dementia and their carers earlier will enable them to keep healthy for longer and more likely to be able to continue living at home.

It is important to note that not all services for people with dementia are provided by the Council or NHS. We have a thriving voluntary sector that provides a range of services; these include: The Alzheimer’s Society, Milestones Trust, Brunelcare and Age Concern amongst others.

Below is a summary of current spending on specialist services for people with dementia, grouped according to the type of service.

Service Type	Level of Need	NHS Bristol Contribution 2010/11 £	Health and Social Care Contribution 2010/11 £	Other £
Carers Support	Low	146,876	277,287	
Day Care	Moderate and substantial	75,000 (est)	1,158,286	
Dementia Advisers/support workers	Self-care to complex	27,000	55,210	Dept of Health Funding £207,000 for 18 months to March 2011
Domiciliary Care (specialist)	Substantial and complex		27,560	
Older People's Liaison Service	Substantial and complex	1,414,000		
Memory Service	Low to complex	346,000		
Older People's Mental Health beds in general hospitals	Substantial and complex	724,592		
Older People's Mental Health Hospital Care with a mental health trust (Day and Inpatient care)	Substantial and complex	4,430,945		
Older People's Community Mental Health Team	Substantial and complex	3,513,583		

Peer Support (Singing for the Brain, Memory Cafes, Drop in sessions)	Low	40,000		
Pharmacy (prescribed medication)	Low need to complex	617,441.93 (in primary care)		
Residential Respite Care	Moderate and substantial	316,550	25,703	
Specialist care home beds	Substantial and complex	3,908,653 (Continuing Healthcare and block beds)	6,459,140 (residential with nursing care)	

What does this information tell us?

From the information above we know that in Bristol we spend a significant amount of money supporting people with dementia within specialist services, the majority of which is spent on specialist mental health services in both hospital and community settings⁸⁰ and nursing and residential care homes. Comparatively little is spent on specialist domiciliary care. This finding goes against the direction of travel for dementia care, which is about supporting more people at home for as long as possible and supporting people within mainstream services wherever possible.

Comparatively we spend a much smaller amount on low level services like peer support, which can support a significant number of people. Again this is against the strategic direction, which is to develop our preventative services (as set out in the draft Prevention and Self Care Strategy). This strategy will provide us with the opportunity to review how these services are commissioned and understand if resources can be more evenly distributed along the care pathway for people with dementia and their carers.

Many people are not supported by specialist provision. So whilst there are very few hours provided of specialist domiciliary care, non-specialist home care services will support a significant number of people with dementia. Similarly whilst there are a significant number of people in homes with a speciality in mental health, a large proportion of people in standard care homes will also have a form of dementia.

We recognise the importance of carers and spend a significant amount of money on services for carers. Informal care is the cornerstone of care for people with late onset dementia. Nationally the Alzheimer's Society (2007) has calculated that the cost of unpaid care amounts to one third of the total cost of dementia care in the UK. We therefore need to ensure we are providing sufficient services to support the carers of people with dementia in Bristol. One of the ways this is being addressed is via the new investment by NHS Bristol into breaks for carers. The needs of carers are fully addressed within our Joint Carers Strategy and the Dementia Strategy will sit alongside this strategy.

Training

Although training is not a service, it is integral to ensuring that people receive the best possible care and appropriate information. The total amount currently spent on training across the health and social care workforce that deliver services to people with dementia is difficult to quantify as there are numerous providers, many of whom provide their own training as well as accessing some of the training provided by Bristol City Council for providers from all sectors. However training is a key element of this strategy and a thorough review is needed to identify gaps in training and skills a workforce strategy will be developed and target resources to address the identified priorities.

Chapter 6: The future of dementia in Bristol

This chapter sets out our priorities for the future based on the data presented in the previous sections.

The future for dementia

As we have noted, the information we currently have limits our ability to accurately identify the number of people who currently have dementia, or will have dementia in the future, although we can make some reasonable estimates. One of our key tasks will be to work on improving our understanding of the future need by improving collection and particularly analysis of the data about service availability, usage and cost. We know that we need to increase the availability of services, but in order for that to be affordable as well as to meet the requirements of the relevant strategies, we also need to change the way services are provided, with more emphasis on lower level and community based preventative services, which will require a shift of resources away from the current focus on specialist services for people with higher levels of need.

What are our priorities?

To achieve this shift in the pattern of service provision, it will require significant effort over the next few years. Some of the change needed will be driven by strategies linked to the Dementia Strategy, such as the Joint Carers Strategy and Putting People First. These changes come at a time of unprecedented budgetary constraint in the public sector. However, there has never been a more important time to review the pattern of services for people with long term health and social care needs such as dementia to ensure that resources are targeted in ways that maximise people's independence, support people to stay at home, support carers and reduce the need for admission to hospital or long term institutional care. The detail of the work needed to deliver the objectives of the Dementia Strategy are set out in the local action plan, which is a working tool and will be developed as issues emerge from the work. There is a lot to achieve, at a time of great change in public services, but in Bristol there is strong commitment to make the changes required to ensure that people with dementia and their carers live well.

Listed below are the priorities for the short term (2011-2012), medium term (2011-2013) and long term (2013 onwards).

Our short-term priorities over the next 12 months are:

- To improve data collection to benchmark the numbers of people using the services, the cost of specialist services and assess value for money
- To raise awareness of dementia amongst both public and professionals and include a “healthy ageing” message
- To commission additional services that will provide peer support to people with dementia and their carers, such as Memory Cafes
- To review the Memory Service and work with GPs to ensure early identification and appropriate referral
- To review training available and ensure it is a contract requirement with all providers that staff are trained to support people with dementia
- To review the domiciliary care provided to people with dementia and ensure the appropriate mix of specialist and non-specialist provision is available
- To audit the use of anti-psychotics in people with dementia and provide training on their use to nursing homes, pharmacists and GPs
- To work closely with care homes in Bristol to drive up quality for all the residents in them.

Our medium term priorities over the next 2 years are:

- To review our use of specialist Intermediate Care for people with dementia
- To increase the number of people with a diagnosis of dementia more in line with expected prevalence
- To have a comprehensive care pathway for any person with dementia, from suspected dementia to end of life
- To work with hospitals to ensure that people with dementia receive a good experience in hospital and that they are not disadvantaged
- To review the capacity of all types of specialist and non specialist dementia services to ensure the right balance is available

- To enable GPs to prescribe dementia medication and have services to better support people in Primary Care

Our long term priorities over the next 3-5 years are:

- To ensure the short and medium term priorities have been implemented
- To review health and social care policy for self care and support in the community and to develop more preventative services
- To build on assistive technology pilots and increase the use of assistive technology where appropriate and to understand the potential added value of telehealth products.

How will these priorities be delivered?

Priority Outcomes	Action	Cost/resources available	Lead Authority
Short term			
Improve data quality	Improve collection and analysis of data on population estimates, diagnosis and value for money	Increase capacity in performance and information team and restructure of commissioning in Health and Social Care. Joint Strategic Needs Assessment Manager now in post.	NHS Bristol & Bristol City Council
Raise awareness among public and professionals	Implement a Joint Communication Strategy Use the existing Dementia Advisors to support this work –	£5,000 each (already committed) £75-100,000 depending on model (Model and cost to be	NHS Bristol & Bristol City Council

	(pilot funding ends September 2011). Ongoing model to be decided.	confirmed and funding identified).	
Improve access to early support and information including peer support and carers support	Memory Cafes to be re-commissioned.	£32,000 (split 60:40 between Bristol City Council & NHS Bristol)	NHS Bristol & Bristol City Council
Improve early diagnosis	Review of the dementia care pathway. Review the Memory Service. GP lead to work with GPs to develop a protocol for identifying patients with dementia. Small incentive scheme implemented to encourage practices to audit dementia register and implement a protocol for diagnosis and recording.	£20,000 from SHA to support this work and further awareness raising (GP's carers)	NHS Bristol
Improve training so that all staff have appropriate knowledge	Develop a workforce strategy across Bristol. Review available	Within existing resources and regional and national funding.	NHS Bristol & Bristol City Council

and skills	<p>training for all groups of staff, especially in hospitals and scope the need.</p> <p>Amend contracts where necessary to include requirement for dementia training.</p> <p>E learning is being developed regionally.</p>	<p>Links with workforce development and strategies across all sectors</p>	
Review role of specialist domiciliary care provision	<p>Participate in regional work on specialist provision.</p> <p>Consider development of internal Bristol City Council specialist service.</p>	<p>Priority for Health and Social Care to develop specification and work with in-house service to develop specialist dementia service.</p>	Bristol City Council
To reduce the number of people with dementia on anti-psychotics	<p>To participate in the national audit for the use of anti-psychotics in people with dementia.</p> <p>To provide training on their use to nursing homes, pharmacists</p>	<p>£13,000 from the Strategic Health Authority to deliver this.</p>	NHS Bristol

	and GPs.		
Improve quality in care homes	<p>To participate in the South West pilot of quality marks for care home for good dementia care.</p> <p>To provide training to staff in care homes that includes pain and dementia and the use of anti-psychotics.</p>	£10,000 from the Strategic Health Authority for pilot.	<p>Bristol City Council</p> <p>NHS Bristol & Bristol City Council</p>
Medium Term			
Commission appropriate level and type of rehabilitation services.	<p>Review of intermediate care. Reablement plans to include provision for people with dementia.</p>	<p>£570,000 funding to NHS Bristol for social care/reablement.</p> <p>£5,650,000 allocated to social care to support reablement.</p>	NHS Bristol & Bristol City Council
Develop new care pathway accessible to all people with dementia regardless of age, disability and ethnicity.	Care pathway work underway – led by GP clinical lead for dementia.	Funded by the Strategic Health Authority £20,000 on early diagnosis.	NHS Bristol & Bristol City Council
Improve care in hospitals	A Joint strategy board across the two Trusts to drive the agenda is set up.	Within existing Acute Trust funding.	<p>University Hospitals Bristol/North Bristol Trust & NHS Bristol</p>

	<p>To review training needs of hospital and other key staff.</p> <p>Implementation of the South West hospital standards for acute care.</p>	<p>Contract levers to be used to incentivise implementation of the South-West standard.</p>	
<p>Review capacity of services to ensure correct mix of specialist and non-specialist provision.</p>	<p>Health and Social Care – Part of the Price Waterhouse Cooper work on domiciliary care and care homes.</p>	<p>Cost to be identified once demand analysis completed, but will be within existing funding.</p>	<p>Bristol City Council & NHS Bristol</p>
<p>To enable GPs to prescribe dementia medication and have services to better support people in Primary Care</p>	<p>Develop a prescribing protocol for GPs. Develop roles in primary care that specifically support people with dementia and their carers – this could be non-clinical and/or clinical staff.</p>	<p>Dementia as a care pathway for urgent care or planned care delivers additional funding via the Quality Outcomes Framework</p>	<p>NHS Bristol</p>
<p>Long Term</p>			
<p>To ensure the short and medium term priorities have been</p>	<p>Action plan in place with appropriate monitoring.</p>		<p>NHS Bristol & Bristol City Council</p>

implemented			
Review Health and Social Care policy for self care and support in the community.	<p>To agree a strategy for prevention and self care agenda.</p> <p>Health and Social Care to have a public consultation on commissioning priorities and development of joint commissioning strategy.</p>	Cost will be built into Health and Social Care medium term financial plan and amended as commissioning priorities are developed.	Bristol City Council
Identify potential for Assistive technology, telehealth, housing and housing related support to help people with dementia live at home.	Link with review of commissioning priorities, especially review of Supporting People programme	Link with reablement funding, use of Assistive Technology will produce savings in other areas.	NHS Bristol & Bristol City Council

Chapter 7: Taking forward the Strategy

How did we consult on the strategy?

A wide cross –section of people with an interest in dementia services were involved or consulted with, for the drafting of this strategy.

Consultation was carried out in a number of different ways including:

- Visits to drop in sessions at the Alzheimer’s Society, to speak directly to people with dementia and their carers, to understand their experiences and what would make their lives easier.
- Dementia Strategy consultation event run in conjunction with Bristol LINK, NHS Bristol and Bristol City Council Joint Health Overview and Scrutiny Committee. This event gave people with an interest in dementia (including carers, black and minority ethnic groups and Councillors) an opportunity to share their views, highlight key issues and provide input into this strategy
- Meetings and presentations to various community groups and individuals
- Dementia stakeholder group, which comprises carers, the voluntary sector, providers, clinicians and commissioners. An event led by the Care Services Improvement Partnership (CSIP) in January 2009 enabled different stakeholders to have early input into shaping future services.
- A primary care summit “Dementia in Bristol” was held in March 2011, to discuss the importance of early diagnosis, the treatment of dementia and to gather feedback on the new care pathway and direction of travel for Bristol.

The draft strategy has been to the Health and Wellbeing Partnership Board (a board of the Local Strategic Partnership), NHS Bristol Professional Executive Committee and Bristol City Council Health and Social Care senior management team and has been viewed by Council members. A 12 week public consultation period took place between June and September 2011. The final version of the strategy has been agreed by Bristol City Council Cabinet, NHS Bristol Board and NHS Bristol Clinical Commissioning Group.

Key themes from the consultation

Strategy

- It needs to link in with other local and national plans and policy.
- There must be clear targets and outcomes from the strategy so that the impact of actions can be monitored and evaluated

Awareness

- Public awareness needs to be improved to make sure people with dementia and their carers are not stigmatised

Training

- All staff needed to be trained in dementia to increase their understanding and awareness. This should include anyone who works in a care setting, including care home staff, all hospital staff, porters, reception staff, nurses, physiotherapists, occupational therapists etc.
- Care home staff require training and support, to adequately support people with dementia.

Carers

- Carers should always be included when thinking about people with dementia
- The needs of carers must be taken into account when developing services
- The needs of people with dementia who do not have family carers should be considered.

GP's

- GP's must understand the importance of a person with dementia being diagnosed in a timely manner

Services

- It is vital that commissioners listen to service users and carers when planning and designing services and that services provided are person centred. When defining the quality of the care experience this should be from the point of view of the service user
- Services need to be joined up and work across sectors to make the best use of resources available and avoid duplication
- Equalities issues must be taken into account when designing services, with clear pathways for all
- People with dementia and their carers would benefit from a named person who they could ask for information at any point
- More low level support such as “Singing for the Brain” (see appendix 1 for details) is needed to enable people to continue living independently at home for as long as possible
- That funding should not be lost/should be increased for people with dementia
- That funding should reflect the needs of people with dementia in Bristol and services be appropriately resourced.

Hospitals

- People with dementia in hospital are particularly vulnerable

Further consultation

We recognise that there will be particular cultural factors for some Black and other Minority Ethnic groups that we are not fully aware of or need to gain further information on and understanding of. We will make contact with specific Black Minority and Ethnic communities (for example the Somali community) and their community leaders in order to demonstrate our recognition of this gap in our information

How will the progress of implementing the strategy be monitored?

Governance and decision-making

To ensure that the vision of the strategy is achieved the Bristol, North Somerset and South Gloucestershire Cluster Board, the Joint Dementia Board and the Health and Wellbeing Local Strategic Partnership Board will monitor implementation progress. These boards will agree challenging targets and timescales to ensure the work plans are being effectively implemented.

The progress of the strategy will be reported on a 6 monthly basis, to the Strategic Health Authority. This will provide an update on progress against the national objectives and local targets.

We will develop clear means of ensuring that the implementation of the strategy is measured such that the data and evidence gained can feed both into the development and improvement of the services and into future commissioning arrangements.

Keeping people informed

Other groups that we will report to, and keep informed of progress are:

- **Bristol Learning Difficulty and Dementia Group:** This group focuses specifically on issues experienced by people with dementia and a learning difficulty. This group links in with the dementia stakeholder group.
- **Bristol LINK:** Bristol LINK is a network of individuals and community groups who work together to improve local health and social care services. Bristol LINK has been involved in the initial consultation phase, hosting the half-day event.
- **Bristol Older People's Forum:** The Forum is independent of the Council and provides a network and a voice for Bristol's older people, putting their views directly to the public authorities.

- **Bristol Older People's Partnership Board:** This group steers the Quality of Life Strategy and is made up of at least 50% older people membership.
- **Dementia Stakeholder Group:** The stakeholder group is made up of representatives from the majority of stakeholder groups in Bristol and includes: Providers, carers, voluntary organisations, clinicians and commissioners.
- **Focus groups:** we will work with the Alzheimer's Society to develop small focus group of carers and people with dementia, to involve them in the delivery and monitoring of the Bristol Dementia Strategy.

Appendices

Appendix 1 – Service Provision

This is a summary of the current services that are provided in Bristol, some are specifically for people with dementia and/or their carers and some are more generic although used by people with dementia and their carers.

Assistive technology

Bristol City Council and Avon & Wiltshire Mental Health Partnership NHS Trust (AWP) have used Assistive Technology in pilot schemes to help promote independence for people with dementia. For example, 'Just Checking' monitors the daily activity of a person in their home and provides a chart of activity via the Internet. Small, wireless sensors are triggered as a person moves around their home. Family members and professionals can view the chart of activity on the Just Checking website.

Just Checking is just one example of Assistive Technology that has been used in these pilots; other examples are bed sensors, memory minders and movement activated sensors, that have all been shown to have positive outcomes for people with dementia and their carers. They allow people with dementia to continue to live independently and can help carers continue in their caring role for longer, by providing some peace of mind.

Carer support groups

There are two carer support groups at Callington Road Hospital which are run in partnership between Alzheimer's Society and The Princess Royal Trust for Carers Centre and there is a support group in Westbury-on-Trym, North Bristol. These offer the opportunity for carers to meet others and share their experiences.

Community Learning Difficulties team

The community team provides holistic healthcare to adults living in Bristol with a learning difficulty. They help individuals to access mainstream health services within primary and secondary care, around all aspects of health, both physical and mental. They provide

specialist input in psychology, speech & language therapy, occupational therapy, physiotherapy, nursing and other related disciplines. Learning Disability Psychiatrists (employed by Avon & Wiltshire Mental Health Partnership NHS Trust) are co located with the community team.

As part of this holistic health care, the community learning difficulties team also works with adults with a learning difficulty who have either a diagnosis of dementia, are exhibiting indicators that suggest that they may be developing dementia or are in a high risk group i.e. Downs Syndrome. The community learning difficulties team has a key role in the diagnosis of dementia in this group of patients, as they require specialist skills to identify dementia .The service aims to develop close links with generic services offering training, support and advice such that people with a learning difficulty are more able to be supported by mainstream healthcare and to access the resources and support being developed under the Dementia Strategy. Once dementia has been diagnosed, as with all other health conditions, the community learning difficulties team's primary role is to facilitate people with a learning difficulty to access and be supported by mainstream services.

Community Nurses for Older People

The Community nurses for older people are registered nurses who work with older people to promote good health and detect an early deterioration of conditions which affect their health and well being. They work closely with other services to ensure each individual can address their own health needs and find support for those who find this difficult. The Community nurses for older people are line managed by the Community Matrons and work closely with GP practice teams.

Counselling

A counselling service is commissioned from Brunel Care for carers, or for people who have just received a diagnosis of dementia. There are a team of 7 counsellors, sessions last one hour and the number of sessions is flexible. The counselling service links into a lunch club where carers of people with dementia can receive a group counselling session.

Day services

Bristol City Council purchases places at specialist dementia day centres across the city, these are: The Roundhouse, Beehive, Humphrey Repton House, The Limes, The Willows, Eastville Day Centre, Tyndale Circle Day Centre.

The Council commission day centres, run by Aspects and Milestones Trust, BrunelCare and Alzheimer's Society which have developed peer support networks for people with dementia and their carers. At one of these centres (The Willows which runs for one day per week) carers are also invited to attend. The carers arrange activities, trips and counselling sessions as a group. This is led by the carers and responds to their identified needs. Carers' lunch clubs also exist and offer the opportunity for informal peer support.

Dementia advisors

Bristol has been part of a Department of Health Dementia Advisor Demonstrator Pilot Project. There were 3 dementia advisors working citywide to signpost people with dementia and their carers to services across the city. This service has now ceased and the outcomes of the evaluation are being considered.

Dementia drop in sessions

Bristol City Council funds a worker based with Alzheimer's Society whose role is to organise peer support drop in sessions for people with dementia and their carers. This gives carers the opportunity to build friendships with people who are in a similar situation to themselves. The Alzheimer's Society support worker attends these meetings. A volunteer befriending scheme has also been developed to offer support to those who do not wish to attend support groups, but still want advice and support. Carers can self refer to this service.

Diagnosis

In Bristol there is a specialist Memory Service, commissioned from Avon & Wiltshire Mental Health Partnership NHS Trust. The Memory Service is based at Southmead Hospital, North Bristol, but is a citywide service.

The diagnosis of dementia is made by either the Memory Service or by the Community Mental Health Team (CMHT). The Memory Service provides assessment, specialist expertise from a psychologist, specialist nurses, medication and medication review. Generally people who attend the Memory Service have no behavioural problems and are able to wait on a waiting list to be seen. People with suspected dementia who see the CMHT may have some acute problems and need to be seen more urgently at home.

The initial basic assessment is carried out by a memory nurse. When all results are returned a psycho-geriatrician will consider any other medical issues make the diagnosis which is then explained to the patient and their carer. At this point it will be decided whether the person with dementia is suitable for drug therapy. If they are not suitable they will be referred back to their GP, with annual follow up appointments with the Memory Service. If they are suitable they be offered a trial for three months, after which the medication is reviewed and the person referred back to their GP to support them and continue to prescribe the medication. They will be reviewed by the Memory Service every 6 months

After this diagnosis the person with dementia will again see a memory nurse or a mental health worker, who offer further support, sign posting and answer any questions that the person with dementia or their carer may have. They will also monitor and review the person with dementia and are also closely linked with the memory cafes.

People with a learning difficulty and suspected dementia are seen within the Bristol Community Learning Difficulties service, which has a multi-professional assessment and diagnosis pathway. Learning Difficulties specific dementia screening assessments are used to identify change over time. Diagnosis is made by a Learning Difficulties Consultant Psychiatrists within the Memory Clinic. Once a diagnosis is made, medication will be considered on an individual basis, which will be closely monitored by the Learning Difficulties Nurse and Consultant Psychiatrist.

After diagnosis the person with Learning Difficulties and Dementia will be monitored by the team as required and followed up within the Memory Clinic. Referrals to other professions (e.g. Speech & Language Therapy regarding Dysphagia), and other services, including Health and Social Care, will be made as required.

Extra Care Housing

Extra Care Housing (ECH) is set up to provide older people with independence in the form of their own flat but within a scheme where they can receive care and support. The final scheme will be opened in the summer of 2012 which will give Bristol 11 schemes across the city providing 600 flats. The flats are one or two bedroomed and there is a choice of housing tenure. The flats can be accommodated by service users who need personal care. If the service user has a partner then they can move into the flat together. The schemes provide a real alternative to residential care.

Extra Care Housing is an option that is appropriate for many people with dementia and can be supplemented by other types of support such as Assistive Technology and more specialist services as people's needs determine.

Intermediate Care and reablement services

These services which are jointly provided by the NHS and BCC cater for all adults including people with mild to moderate dementia. A review has been undertaken in 2011 and the services are being redesigned and improved to help more people remain at home for longer. In addition a new reablement service is being developed specifically for people with more severe dementia who are at risk of admission to hospital or long term care.

Learning Difficulties Hospital Liaison team

The Hospital Liaison nurse team exists primarily to provide advice and help to people with a learning difficulty in acute care settings, regarding their physical, emotional and psychological healthcare needs.

Memory Cafes

Following a pilot in 2008, 3 cafes have been commissioned from Alzheimer's Society in conjunction with Age UK to support people with dementia and their carers following diagnosis.

Memory Management course

Avon & Wiltshire Mental Health Partnership NHS Trust provides a course for people who have received a diagnosis of dementia and or the family/carer. This is done in the form of peer support with 8 pairs in a session. The session offers some education about what dementia is, developing strategies and ways to cope with the dementia.

Older People's Psychiatric Liaison

A specialist cross-Trust Mental Health Liaison team for older people was introduced in June 2008. The establishment of this team has marked a major step towards a fully multi-disciplinary approach to supporting people with dementia in acute hospitals.

The team's work is focussed on Acute (main) Hospital Wards where there is a high proportion of Older People with cognitive (function) impairment and/or diagnosis of dementia, depression, confusion and anxiety. The team provides a service to University Hospitals Bristol at the Bristol Royal Infirmary and North Bristol NHS Trust, at Southmead and Frenchay Hospitals.

The team has had a significant impact on the service, assessment and care older people with cognitive impairment/dementia and other mental health disorders receive in hospital, and has helped to ensure better health and wellbeing outcomes.

Peer support

NHS Bristol commissioned 9 new peer support groups in 2010. These groups are provided by the voluntary sector and provide support to people with dementia and their carers. Groups have been commissioned from: Age Concern, Alzheimer's Society, Bristol and Avon

Chinese Women's Group, Life Cycle, Somali Disability and Elderly Group and Reminiscence Learning. These groups provide a variety of activities including art classes, tandem cycling and music groups.

Private Sector Care Home Provision

There are 42 care homes in Bristol providing nursing care of which 9 offer care for people with dementia. There are also over 120 residential care homes in Bristol, of which 11 cater for dementia. However it should be noted that many of these homes are able to cater for the needs of people with mild cognitive impairment.

Residential homes

Bristol City Council is currently undertaking a review of the care homes it provides. There are currently 13 care homes for older people, of which 5 offer specialist dementia care.

Singing for the Brain

Singing for the Brain is run by Alzheimer's Society and takes place in four venues across the City. Between 25 and 40 people attend weekly sessions. 'Singing for the Brain' is a therapeutic and social activity for people with neurological conditions and their carers. It is an opportunity for people with dementia to participate in singing sessions together, in an informal and friendly setting aimed at providing an enjoyable activity, which stimulates mind and body.

'Sitting' Services to support carers

BrunelCare are commissioned to provide a 'sitting' service to provide a break for carers. They offer person centred care and have a flexible approach to the services they offer, which are determined at the care planning stage. Depending on the outcome required, they may take the person to a café, make things with them at home, or just provide company and sit with them while they watch television. As part of the delivery of the Carers Strategy in Bristol, work is also under way to develop alternative ways in which carers can be supported flexibly.

Specialist Care Homes with nursing

Bristol commissions 55 specialist dementia beds, at Humphrey Repton House and Somerset Lodge – commissioned from Aspects and Milestones Trust and Treetops – commissioned from Shaw Healthcare. These beds are for people with dementia who need a high level of specialist care. By commissioning these beds, there has been a reduction in hospital length of stays and a reduction in admissions to hospital for people with end stage dementia.

Specialist Dementia Domiciliary Home Care

Bristol City Council purchases specialist home care provision from Aspects and Milestones Trust, for people who need a high level of individual support. The Milestones Outreach Dementia Services (MODS) provide specialist home care services for people with dementia who are living at home. They offer person-centred planning that emphasises individual choice and preference while focusing on the need for personal safety, emotional support, stimulation, carer support and personal care. The team provides a flexible package of home care that enables a person to remain at home for as long as possible. Where possible the same person visits at the same time to minimise confusion.

Specialist in-patient units for older people with mental health problems

Malvern is a dementia ward at Southmead. If people are admitted to hospital and their physical condition is stable, but there is suspected dementia, people are admitted to this ward. If people exhibit challenging behaviour or require further assessment by a specialist unit they are admitted to Avonmead ward.

Callington Road Hospital provides specialist mental health wards for people with dementia and for older people with mental health needs.

Appendix 2

Glossary

Term	Explanation
Acute Trust	An NHS body that provides medical and surgical services from one or more hospitals.
Anti-Psychotic	A medication used to treat any mental disorder that involves a loss of contact with reality.
Carer	Someone who unpaid, provides help and support to someone who could not manage without their help.
Commissioning	The way that the local authority and NHS plan, organise, and buy services.
Consultation	An opportunity for discussion or the seeking of advice.
Day care	Day care is usually provided at a centre, and offers a wide range of services from social and educational activities to training, therapy and personal care.
Domiciliary Care	This means services provided at home, that help people to live independently within the community.
Early Intervention	Interventions targeting people displaying early signs and symptoms (of dementia).
Equalities	'Equalities' refers to the range of work aimed at ensuring the full and fair participation of marginalised or under-represented groups arising from discrimination, disadvantage and other barriers to participation. This has a particular reference to race, disability, gender, sexual orientation, religion or belief, and age.
Health and Social Care	The department in Bristol City Council who are responsible for adult social care.
Home Care	Home carers are people employed by health and social care and are paid to care for you in your own home.
Intermediate Care	Services to support people between hospital care and regular social care at home. Often this support is for people coming home from hospital, or to prevent people going to hospital.

Intervention	An action to change/alter a development.
Mainstream Services	Services available to anybody with a need (not specifically for people with dementia).
NHS Bristol	Is a statutory (legal) body which is responsible for delivering health care to local communities through GPs, community nursing staff and other primary care staff.
Peer support	Services that are designed so that people are able to gain support from other people in the same situation or with the same condition.
Personal care	Care provided to a person who needs extra support. Personal care includes help with washing and dressing, getting up and going to bed, and other daily tasks.
Preventative services	Services put in place to keep people well for longer.
Primary Care	The first point of contact for patients, usually based in the community. This includes GPs.
Provider	Any person, group of people or organisation supplying a service. Providers may be either statutory (set up by government/legislation) or non-statutory people or organisations.
Secondary Care	Specialised treatment usually provided by a hospital
Specialist Services	Services that are designed to support a specific condition or group of people.
Strategy	A plan of action designed to achieve a particular goal
Voluntary Sector	Organisations, often charities, which operate on a non profit-making basis, to provide help and support to the group of people they exist to serve. They may be local or national, and they may employ staff, or depend on volunteers.