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“Give me something to believe in”

BIRMINGHAM AND SOLIHULL DEMENTIA STRATEGY

2014-17







We are clear about the responsibility that our organisations have to help shape and deliver a better model of health and social care for the people of Birmingham and Solihull who have or may develop dementia, that takes into account the differences across the area but still builds a consistent response to the challenges presented. As leaders of our organisations we commit to work together, in partnership with the people of Birmingham and Solihull, to create this model, and ensure it meets the needs of people with dementia, their families and carers, delivers better outcomes and reduces inequality.

Chief Officer, Birmingham Cross City Clinical Commissioning Group

Chief Officer, Birmingham South Central Clinical Commissioning Group

Chief Officer, Sandwell and West Birmingham Clinical Commissioning Group

Chief Officer, Solihull Clinical Commissioning Group

Chief Executive, Birmingham City Council

Chief Executive, Solihull Metropolitan Borough Council

Director of Public Health, Birmingham City Council

Director of Public Health, Solihull Metropolitan Borough Council

Chief Executive, University Hospital Birmingham (UHB)

Chief Executive, Heart of England Foundation Trust (HEFT)

Chief Executive, City Hospital

Chief Executive, Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT)

Chief Executive, Birmingham Community Healthcare Trust (BCHC)

Health and Wellbeing Board Birmingham

FOREWORD

As a GP and now a commissioner who has been involved in dementia for almost 20 years, I cannot understate the importance of this strategy. It is purposefully created at a high level, setting standards for the care that the people of Birmingham and Solihull tell us they want and should get.

We have asked carers and people with dementia what they want and used this to build a strategy 'from the bottom up', and tried to focus more on outcomes for people with dementia and their carers.

What is clear to me is that while we have many exceptional services locally, they do not coordinate or communicate adequately, they are inconsistent in availability, and they are sometimes difficult to locate. This strategy is designed to challenge providers and commissioners of care for people with dementia, to identify how they can improve what they do and set plans to achieve better services.

Dementia is not a normal part of growing old. We know from what people have told us that it is possible to have a really good life with dementia, but we also know that many people's experience of living with dementia has been poor and that there are lots of things that we can do better. For example, support following a diagnosis is not consistent. We know that the care of people with dementia in acute hospitals and care homes often falls short of the standards that we believe are acceptable, and we know that people with dementia are often not treated with dignity and respect.

This strategy has been developed following consultation with large numbers of people currently accessing dementia services who have told us what would improve their experience and help them to be able to live well with dementia.

In 2012 the Chief Executive Officer of Birmingham and Solihull Mental Health Foundation Trust and I gave our assurances to a large number of carers and people with dementia that services would be improved. With this strategy, I believe we can make a difference.

Dr Patrick Brooke
Chief Officer
NHS Solihull CCG

The need to provide people with dementia and their carers with the information, support and care that they require is one of the greatest challenges facing not only the NHS, but our whole society at the present time. Dementia remains a subject largely ignored and often not spoken about, as it arouses so many feelings of fear and anxiety. It's something that people don't want to contemplate having, and don't know how to deal with. We must ensure that we face this challenge locally and change services to give people more information about dementia and more co-ordinated support and, where necessary, that we are able to provide direct care and compassion to patients who are left so vulnerable with the illness.

John Short
Chief Executive Officer
Birmingham and Solihull Mental Health Trust

> “Dementia is not a normal part of growing old. We know from what people have told us that it is possible to have a really good life with dementia, but we also know that many people’s experience of living with dementia has been poor and that there are lots of things that we can do better.”

EXECUTIVE SUMMARY

The people best able to tell us what is good and not so good about dementia services are the people who use them. This high-level dementia strategy is, therefore, based upon what people in Birmingham and Solihull have told us they would want from dementia services and the support that they have said will help them to live well with their dementia.

The experiences of some people were good; some were incredibly distressing. Far too many were poor, and this highlighted an inconsistency of provision and quality across Birmingham and Solihull.

The strategy covers the five main parts of our dementia pathway:

- Prevention and Health Promotion
- Recognition and Identification
- Assessment and Diagnosis
- Living Well with Dementia
- Increasing Care (Including End of Life Care)

For each part of the pathway, we focus on:

- What people have told us
- The case for change
- Local and national best practice
- Key actions / next steps

Why Do We Need To Change?

We know that people are living longer and we anticipate that this will result in an increase in the number of people with dementia. Currently, we estimate that there are 13,819 people in Birmingham and 2,798 in Solihull with dementia[1]. This is predicted to grow by 31 per cent to 3,800 in Solihull and by 18 per cent to 16,300 in Birmingham by 2021.

Overall, the proportion of people from Black and minority ethnic (BME) groups affected by dementia is broadly the same as for the white population. There appears, however, to be a higher incidence of vascular dementia and early onset dementia in BME communities, particularly Black Caribbean and Asian[2][3]. We need to make sure that services meet the needs of these communities.

We know that the needs of people with early onset dementia (under 65 years old), and with learning disabilities who develop dementia, differ radically from those of older people with dementia.

The prevalence of dementia for people with a learning disability is significantly higher than that of the general population and, with extended life expectancy, the number of people with learning disabilities who develop dementia is increasing. Again, this has important implications for how services are developed to ensure that they meet need.

We estimate that the current total cost of dementia in terms of health and social care is £90m for Solihull and £300m for Birmingham, and that this will grow to £120m for Solihull and £350m for Birmingham by 2021[4].

We know from work locally and nationally that if we had the right services in place in the community we could prevent some of the very expensive episodes we list above. People with dementia, their carers and their families, agree with us.

Even without the demographic growth predicted, we are facing reduced public funding, which makes the current levels of costs unsustainable. Large-scale transformation of the current dementia care system is therefore required so that we can live within our means.

What next?

Prevention and Health promotion

We want to develop communities that are dementia friendly, that will help to reduce stigma and that will promote equality. Key to this is the development of local information sources, as well as campaigns to increase awareness of the condition. This will be through national projects such as work in schools, Dementia Friends and Champions, and Dementia-Friendly Communities, as well as local publicity and awareness raising.

We shall seek to embed a culture of wellbeing and the promotion of independence across all health and social care services.

We also know that certain groups of people have higher dementia risk factors and, again, GPs need to be more proactive in identifying these patients and regularly screening them once they have turned 60.

We know that we have a very diverse community across Birmingham and Solihull and that one size will not fit all. We will work with these communities to better understand what they need to help them to better support those with dementia.

Recognition and identification

Getting an early diagnosis relies on professionals being able to recognise and identify symptoms of dementia. In Birmingham and Solihull recognition and identification occurs mainly in primary care. But we know from what people have told us that there are many barriers, not least people themselves, which prevent early diagnosis.

We are looking to address these barriers through awareness campaigns which highlight the benefits of a diagnosis. We want people to see that the diagnosis is the gateway to getting the help and support that they need to help them live well with dementia. To improve recognition and identification we need to ensure that GP's and wider primary care staff have appropriate dementia training and support to help them identify people with dementia and to feel confident and competent in supporting their patients' needs post diagnosis.

Assessment and diagnosis

The strategy considers in more detail the benefits that an early diagnosis brings. We need to be very clear that support for people with dementia is not about the diagnosis, 'it is about what happens afterwards'.

In this part of the strategy the focus is, therefore, on making sure the process of assessment and diagnosis is easily navigated by people, that afterwards, they are helped to come to terms with their diagnosis and plan for their future, and that they are able to get the information and support they need to do this.
That said we know that, while we are working to increase the number of people with a diagnosis, this will increase the number of people who will go through the gateway and who will need access to appropriate services and support. This will increase service demand and spend, and we need to ensure that services are in place that can respond to local needs and to the clear desire of people to remain independent for as long as possible.

Living well with dementia

We want to ensure that people who are diagnosed with dementia have access to the specialist advice and information that they need to understand what having dementia will mean to them and their family and in a format that suits them. That their diagnosis helps them to access the support that they need instead of it being used as a reason for exclusion. That they can get the right information and advice to help them plan for their future. We want to make it easier for people to find the services that will meet their needs, in the way that they want them met, recognising that one size doesn't fit all.

> “We know that we have a very diverse community across Birmingham and Solihull and that one size will not fit all.”

We want to address the shortfalls in provision for carers by ensuring that their needs are assessed and reviewed regularly. It is essential that carers have access to appropriate information, advice and training so that they are able to feel confident in their caring role. There will, however, be times when the carer is struggling to cope and they need to be able to rely on help being available quickly when they, or the person they are caring for, are in crisis.

We know that there are many organisations in our communities who are already supporting people with dementia, or who would be keen to open up their activities to people with dementia; we want to be able to develop capacity in these organisations.

Increasing care (including end-of-life care)

We know that people's needs tend to change over time and that we need services that are flexible and adaptable in meeting changing needs and demands. We know that there will always be a need for hospital and care home admissions but feel that these are over-used currently because community services that might prevent unnecessary admissions, are not available for people with dementia. We know that this has a massive impact in terms of cost and the quality of care, as well as not being what people want.

We also know that the quality of dementia care in acute hospitals and care homes varies, and that the experiences of people with dementia accessing hospital and care home services are often poor.

We are working with our partners to improve these quality and access issues, and the strategy includes some local examples of best practice.

These include: improving access to staff training in dementia, encouraging services to develop their environments to be dementia friendly, providing specialist training to hospital and care home staff in the management of challenging behaviour and in the use of non-drug interventions as a viable alternative to the prescribing of anti-psychotic medications. We also need providers to embed end-of-life planning and to improve options at the end of life for people with dementia.

The way forward

In our strategy we recognise that there is still a long way to go until we can say that we are providing high quality care and support in a way that best meets the needs of people with dementia and in ways that are cost effective.

We also have to acknowledge that no one agency can do this alone. Dementia is everybody's business and it is, therefore, reliant on a coherent partnership framework across health, social care and the third sector.

To see our video visit **www.vimeo.com/63396880**.
To access the paper copy of 'Connected Compassionate Communities' **Click here**

INTRODUCTION

In order to find out what people locally thought about current dementia services and what they felt would meet their needs, we commissioned a creative program of work called **'Connected Compassionate Communities'** across Solihull and the East and North of Birmingham.

Through this we were able to interview service users and carers to build our strategy 'bottom up'. The program produced a wealth of information about the local picture that we were able to build on further through the consultation event held in the Autumn 2012.

What have people told us?

People with dementia say:

- That there is still a lot of stigma attached to dementia and this means that people try to cover it up for as long as possible
- That they struggle to find out what is available to support them and how to access it
- That there are good services and support available but that it takes a lot of effort to find them
- That their experience of getting their GP to take their worries seriously has been patchy
- That services do not appear to be co-ordinated
- That they want to be able to stay living at home for as long as possible
- That they want to be supported to continue to do the things that are important to them and to have a choice in the type of services available to support them
- That the diagnostic process sometimes takes a very long time, which increases their concerns and means that they do not feel able to access services that would support them.

Carers say:

- That support for carers is poor
- That they want to continue to provide care but need to be able to rely on the wider services and know that help is available quickly when things became difficult
- That there is not enough respite care available and very little that is not residential.

To see our video visit: **www.vimeo.com/61190089**. To access the paper copy of 'Connected Compassionate Communities' **Click here**

Vision and values – Birmingham and Solihull

Our vision is that people in Birmingham and Solihull living with dementia will have improved health and a better quality of life. We have included statements below from national work to summarise what we want people to be able to say about their experiences:

- I was diagnosed early
- I was treated with respect and dignity
- I feel supported as a carer
- I got the right information, at the right time in the right way
- I have GP Support
- I enjoy life
- I was given information about the end of life to make informed choices
- I am able to continue to do the things I enjoy and have opportunities to try new things
- I feel understood by the professionals who treat me
- I have choice, control and knowledge of services
- I am supported to do things/activities at home
- I understand, so can make decisions
- I received continuity of care
- I was treated with respect and dignity whilst managing my condition
- I get good support and breaks as a carer
- I feel part of a community and I'm inspired to give something back

Adapted from A Call to Action: The National Dementia Declaration[5]

> "There is still a lot of stigma attached to dementia and this means that people try to cover it up for as long as possible."

What is dementia?

Dementia is a term used to encompass a group of illnesses that cause progressive damage to the brain resulting in its function being impaired.

People with dementia may have problems with:

- Understanding
- Memory
- Changes in their behaviour and mood
- Communication
- Day-to-day activities such as cooking and personal care
- Falls
- Managing their own health.

As we get older most of us find that our brain is not as good as it used to be, however, this is normal and reduced cognitive ability through normal ageing is NOT dementia.

- Dementia can affect everybody, irrespective of gender, ethnicity or class.
- Dementia can affect adults of working age as well as older adults.
- Dementia is more prevalent in people with learning disabilities, multiple sclerosis, motor neurone disease and Huntington's disease.

Understanding how the disease may progress can be useful in helping someone with dementia and their family anticipate and plan for the changes that may occur.

Dementia becomes more common the older you get, with an incidence of one in twenty people aged over 65 years, one in five over 80 years, and approaching almost one in three by age 90.

Why do we need a dementia strategy?

The overarching purpose of this strategy is to understand the current experiences of people with dementia, to identify what we already have in place that is working well, and to identify what we still need to do to improve the outcomes for older people with dementia and their carers.

This strategy has been developed to begin a process of a planned and co-ordinated approach to the delivery of a range of services to support people with dementia and their carers.

The strategy will be used as an integral part of the planning and decision-making process across Birmingham and Solihull. It will ask all partners to define how they will redesign their current services to ensure that people with dementia have access to the high-quality provision that they need to help them to live well with their dementia. It is no longer acceptable for dementia to be a diagnosis of exclusion. We want to ensure that the money that we are spending and plan to spend on the care and support of people with dementia and their carers will make a real difference to them.

Strategic drivers to commissioning dementia services

There are a number of national strategic drivers that have helped to shape the strategy. These include:

The National Dementia Strategy, 'Living Well with Dementia' (2009)[6] sets out a vision that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia, no matter what the stage of their condition or where they are in the health and social care system. This approach is inclusive of all types of dementia in all groups affected, including people under the age of 65.

These key themes were carried through into **'Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy (2011)**[7], the updated implementation strategy for the 2009 strategy, and **'The Prime Minister's Challenge on Dementia – Delivering Major Improvements in Dementia Care and Research by 2015**[8], which explicitly described the imperative for the Coalition Government in terms of dementia.

THE CASE FOR CHANGE

We have made a commitment locally to ensure that a diagnosis will give access to services that help people to live well with dementia. We recognise that one implication of this commitment will be the need for increased investment in support that helps people remain at home, and a move away from a reliance on residential or acute care where it can be avoided.

Our dementia strategy

Listening to people who have dementia and their carers and families has provided us with the core evidence and outcomes to inform the strategy. People told us that they felt current services wouldn't provide them with what they needed, and this was one of the reasons they didn't come forward as early as they should to get a diagnosis. We have made a commitment locally to ensure that a diagnosis will give access to services that help people to live well with dementia. We have made a commitment locally to ensure that a diagnosis will give access to services that help people to live well with dementia. We recognise that one implication of this commitment will be the need for increased investment in support that helps people remain at home, and a move away from a reliance on residential or acute care where it can be avoided.

The experience of other areas of the country shows that these community services can be provided as part of a more cost-effective model. This will allow the increased numbers we expect to access the services they need at an earlier stage. This is part of a clear message to commissioners about where the focus needs to be in terms of the delivery of good dementia care. In this section we look more closely at the evidence that supports this message.

Increasing numbers – population growth

We know that people are living longer across the world as a whole. In 1901, people living in England had a life expectancy of 45 years for men and 49 years for women. By 2012 this had increased to 79.2 years for men and 83.3 years for women[40].

The gains in life expectancy that have been seen over the past few decades (especially in high-income countries), and that we project into the future, are predominantly associated with reductions in age-specific death rates at middle and older ages. These reductions are typically associated with improvements in medical technology, lifestyle changes, and income growth. The reality of this is many more older adults.

Locally, the 2011 census shows that, for Birmingham, the number of people who are 85 and over has increased (as part of an overall local population increase of 9.8 per cent) since 2001. This means that people aged 85-plus now make up 1.8 per cent of Birmingham's population – around 19,000 people – and for Solihull 2.7 per cent, or 5,501 people.

Prevalence rates for dementia in the UK are well established so we can anticipate that one in six people over the age of 80 currently have, or will develop, dementia in coming years. For Birmingham and Solihull we know that the rates of growth differ but we estimate numbers will grow by around 18 per cent and 31 per cent respectively, in other words, by around 1,800 people in Birmingham and 900 people in Solihull by 2021[41].

> “Prevalence rates for dementia in the UK are well established so we can anticipate that one in six people over the age of 80 currently have, or will develop, dementia in coming years”

> “People with learning disabilities have an increased risk of developing dementia as they age.”

What does the increase look like for Birmingham and Solihull?

Figure 1 Demographic change in Birmingham for the period 2011 – 2021[12]

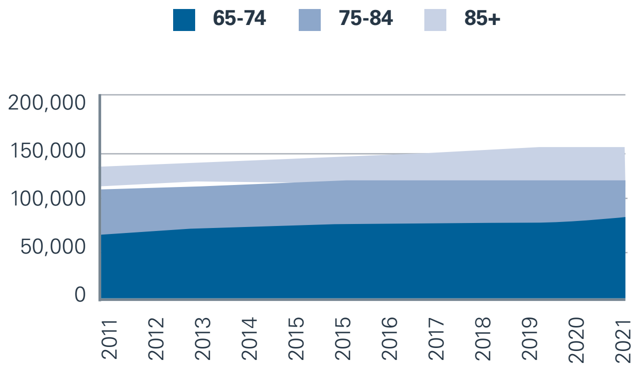
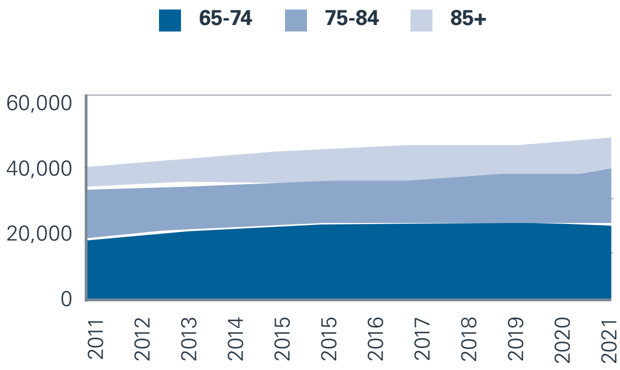


Figure 2 Demographic change in Solihull for the period 2011 – 2021[12]



Birmingham: On average the population in Birmingham aged 65 or over is estimated to increase by an average of 1.1% per year (1.1% 65 to 74, 0.3% 75 to 84 and 3.0% 85 and over).

Solihull: On average the population in Solihull aged 65 or over is estimated to increase by an average of 2.0% per year (1.1% 65 to 74, 2.2% 75 to 84 and 3.9% 85 and over).

Figure 3 Estimated growth* in the number of people living with dementia in Birmingham in the period 2011 to 2021

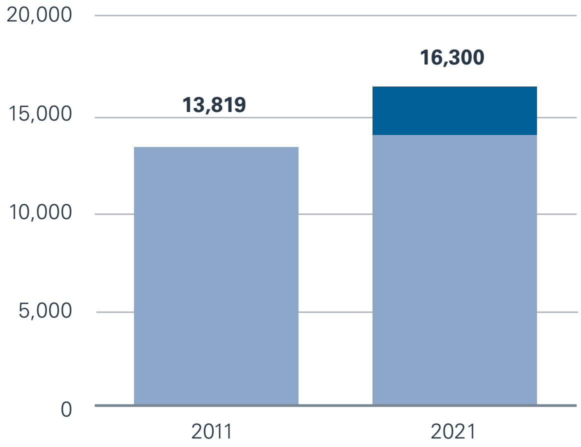
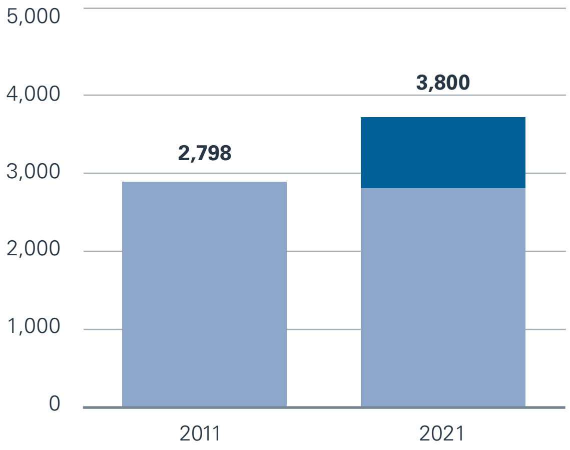


Figure 4 Estimated growth* in the number of people living with dementia in Solihull in the period 2011 to 2021



Note: * Estimated number of dementia cases based on national prevalence rates reported in Dementia UK: Alzheimer's Society, 2007. Sources: Dementia UK: Alzheimer's Society, 2007. ONS population projections interim 2011-based.

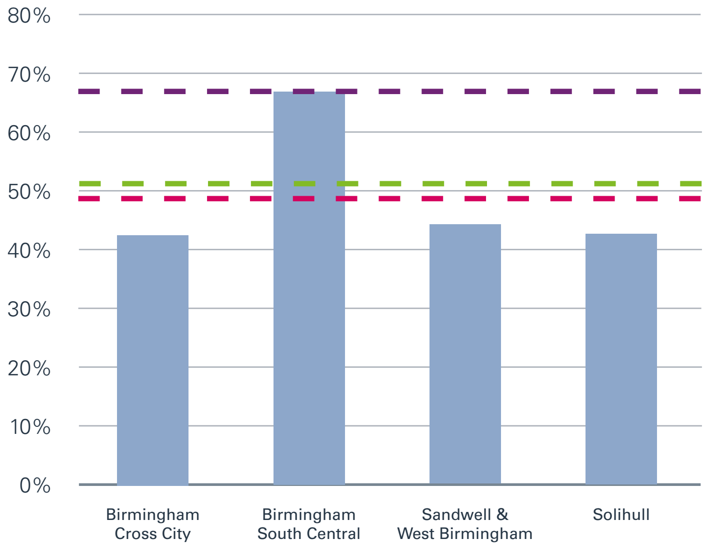
We can also identify specific increases such as in the number of older black and minority ethnic (BME) people in the UK that are likely to lead to an increased need for dementia services for these groups.

Nationally it is estimated that there are at least 15,000 people[10] from black and minority ethnic (BME) groups with dementia. Around 6.1 per cent of all people with dementia among BME groups are young onset, compared with only 2.2 per cent for the UK population as a whole, reflecting the younger age profile of ethnic minority communities. Many services for people with dementia from these communities, however, remain inappropriate and inaccessible. This can be due to a range of issues including language barriers, not knowing what help is available, or traditional beliefs about dementia that inhibit people seeking help, as well as an established culture of caring for older people in the family. For Birmingham, the 2011 census showed 42.1 per cent of Birmingham's population classified themselves as part of an ethnic group other than white British (that is around 451,409 people). For Solihull, this figure was around 29,426 people, or 14.2 per cent[10]. This represents a significant driver for ensuring inclusive services.

People with learning disabilities may experience a higher risk of dementia. People with Down's Syndrome have an increased genetic risk of developing dementia. Additional specialist support and services need to be provided to meet their increasing needs.

How many people in Birmingham and Solihull have a diagnosis currently?

Figure 5 Number of people diagnosed with dementia as a percentage of those estimated to have dementia, by CCG area[14].



This chart shows the diagnosis rates for Birmingham and Solihull Clinical Commissioning Groups (CCGs). This data is used as an indicator of how successful CCGs are at recognising and recording when their patients have been diagnosed as having dementia.

Increasing numbers – increasing diagnosis rates

Why do we want to increase diagnosis rates? One important reason is that people want to know what is wrong with them. Assessment of symptoms can also help to identify other health issues that may be treatable – a diagnosis should be the gateway for people to access the services they need and an early diagnosis will ensure that people are given the most appropriate support earlier thus delaying the need for more intensive services.

This should reduce the average cost of caring for someone with dementia.

However, this strategy isn't about saving money, it is about ensuring that the money is invested in the services that will make the most difference to people with dementia and their carers in helping them to live well with their dementia.

While three out of the four local clinical commissioning groups have diagnosis rates higher than the national average of around 46 per cent (including one – Birmingham South Central – with a rate of 67 per cent), there is still concern about those people who do not receive a diagnosis. Nationally this is reflected in a proposed new ambition of 67 per cent by March 2015.

The financial case for change

It is possible to estimate very broadly the total economic costs of dementia, based on previous modelling that calculated the 'economic burden' of dementia, including healthcare, long-term care and informal care and other costs[16]. This estimated the cost of dementia to the UK economy at around £23 billion per year, of which social care made up 40 per cent (based on an estimated 37 per cent of all people with dementia in the UK living in a care institution), carers and productivity losses a further 55 per cent, and health care costs around 5 per cent.

Simply dividing the total estimated cost by the estimated number of people with dementia (821,884) allows us to estimate a cost per person per year for dementia of around £27,647. This contrasts with the cost per cancer patient of £5,999, stroke £4,770, or heart disease £3,455. Additionally of note is that, compared with cancer, stroke and heart disease, the costs for social care for a person with dementia substantially outweigh those for healthcare.

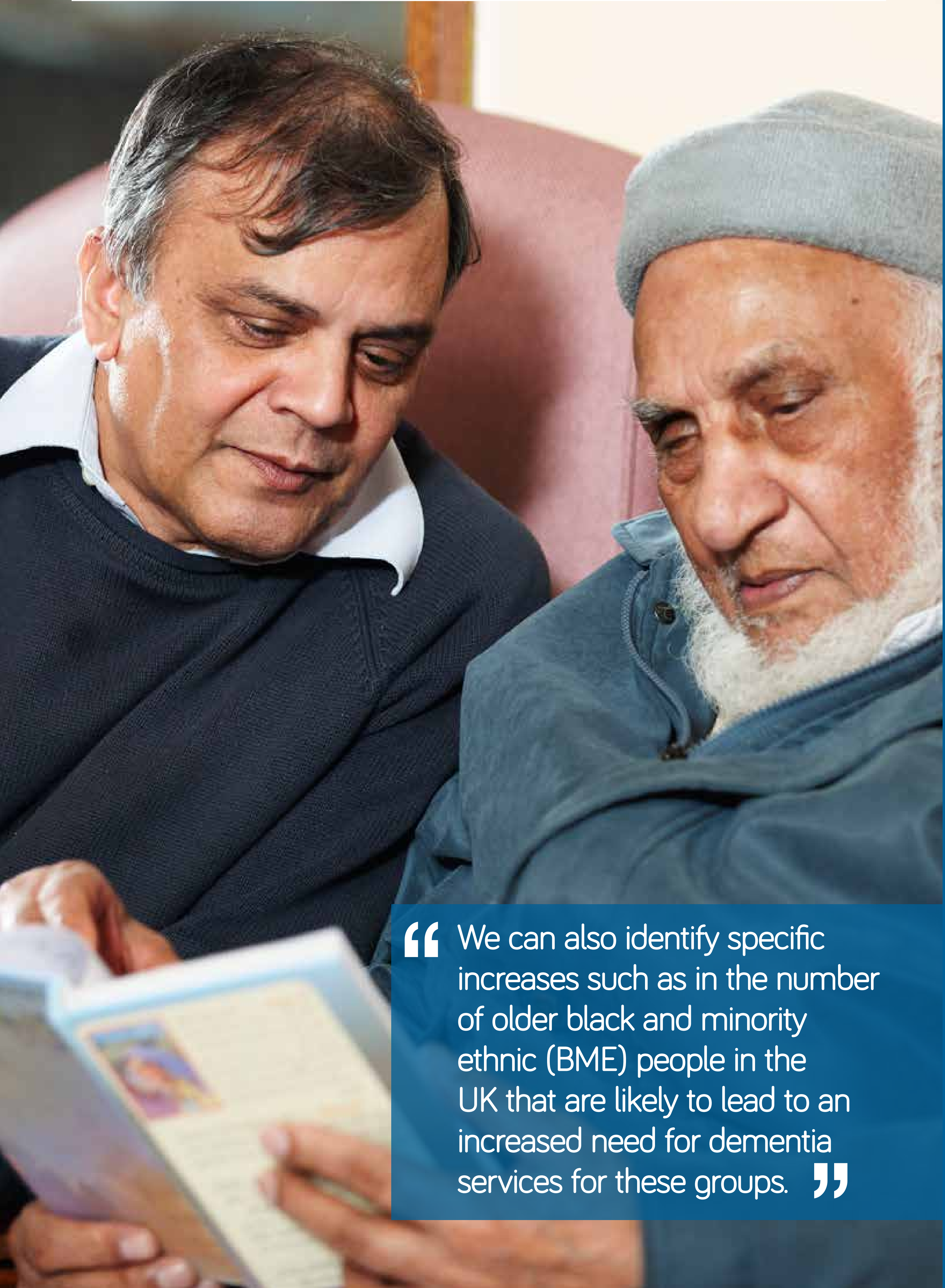
The same report estimated that, in 2006, there were more than seven million primary care consultations in the UK due to dementia, with nearly 50 per cent of them being GP home visits. There were almost 300,000 Accident and Emergency visits, and close to 500,000 outpatient appointments. Around 1.5 million inpatient bed stays and day cases had a primary diagnosis of dementia. These figures were substantially higher where dementia was an underlying cause rather than the primary diagnosis. From this we can build a picture of the current annual costs of around £90m for Solihull and around £300m for Birmingham, across the health and social care sector.

Combining this with the predicted growth in numbers of people with dementia (based on demographic change) of 31 per cent for Solihull and 18 per cent for Birmingham (i.e. a total of around 2,700 people) by 2021, this would increase the annual costs to around £120m for Solihull and £350m for Birmingham.

While we know something about the extent of the costs, it is quite difficult to accurately pin down the actual costs/spend as it is distributed across a range of services/provision. What we do know is that, of this spend, only a small proportion goes on the assessment and early interventions (around £3.5million) that represent the backbone of the dementia pathway. The majority is absorbed as:

- The cost of emergency admissions to acute hospitals for physical health problems that in other groups may possibly have been managed in the community
- Additional staffing in hospitals to ensure safety where people have dementia
- Much longer stays in hospital than people with similar conditions but no dementia
- Going into a care home when provision at home might have prevented it.

> “It is possible to estimate very broadly the total economic costs of dementia, based on previous modelling that calculated the 'economic burden' of dementia, including healthcare, long-term care and informal care and other costs.”



> “We can also identify specific increases such as in the number of older black and minority ethnic (BME) people in the UK that are likely to lead to an increased need for dementia services for these groups.”

In addition, while we are facing greater demand, government investment in health and social care is static or reducing, creating a significant driver for change.

The way forward

We know from the experience of other areas that:

- By providing support earlier to people that have a higher risk of dementia we can potentially delay the onset of the disease[17]
- By providing the community support and community services that people with dementia want and need, we can improve their quality of life while reducing emergency hospital admissions and premature admission to care homes, i.e. deliver better services in a more cost-effective way
- By supporting the families and carers of people with dementia we can help people to remain independent for longer.

The case for cost-effective services and support with a primary care focus is built, not just on the delivery of treatment interventions in a community setting, but on a network of support that covers the breadth of health and social care services. These range from intensive home treatment services to the use of home adaptations and telecare equipment, of which there are many available and which can bring savings. We know that we need to use a long-term conditions approach as the majority of people with late onset dementia will have other chronic physical health problems and/or co-morbid mental health problems. The progressive nature of dementia means that most people will have changing health and social care needs that need reviewing over many years.

PREVENTION AND HEALTH PROMOTION

1. Raising awareness and understanding

> *"I have a sense of belonging and of being a valued part of family, community and civic life."*
>
> *"Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive."*
>
> **National Dementia Declaration – A Call to Action**

Background

People with dementia and their carers told us that they did not always have a sense of belonging and often felt that they were 'stigmatised' and this limits their opportunities to enjoy the same options as others. It also discourages people who might otherwise seek a diagnosis.

Many people spoke of themselves and/or their carer being excluded from some of the activities they previously took part in, either because of explicit exclusions, or because of the attitudes of staff or other people. This increased their social isolation, making it more difficult for them to get the support they needed.

We know that public understanding of the disease is limited, with people not understanding the condition or how they can support those affected by it to 'live well'[18]. The Department of Health campaign in 2012 encouraged people to learn about dementia.

It was aimed at raising awareness of the condition, the early signs and symptoms, and how to seek help.

Lower levels of awareness about dementia and the existence of stigma within minority ethnic communities can help explain why people from these groups are currently under-represented in dementia services.

Case for Change

People did not always have a sense of belonging or that their contribution was sought or valued, and often felt marginalised. Feeling they are no longer a part of their community can lead to people with dementia and their carers giving up their interests, as they feel uncomfortable carrying on.

Some people reported a lack of understanding among family members, and even among health professionals, including their GPs.

Best Practice

Local work involved two schools - Swanshurst School in Birmingham and Heart of England School in Solihull. This was helped to promote learning about dementia through lessons, visits and other local activities.

Define the Changed State

I will be less frightened of dementia.

I will experience fewer feelings of stigma because of my dementia. I will see more positive images of people with dementia.

My community will be developed and enabled to better understand and support people with dementia and their carers.

> “Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.”

Key Actions

1. Agree a local public information campaign, training and awareness raising.
2. Include dementia in local strategic planning.
3. Include early identification of dementia as a priority for health and social care services.

PREVENTION AND HEALTH PROMOTION

2. Wellbeing health promotion, prevention, delaying onset

> *"I will have access to services that keep me healthy."*
>
> **National Dementia Declaration – A Call to Action**

Background

The part a healthy lifestyle can play in lowering the risk of developing dementia as well as cardiovascular diseases, such as strokes and heart attacks, is well documented[19]. In response to this, the NHS Health Check risk assessment for those in the 65-74 age group has been extended to include dementia. This is aimed at raising awareness among health staff as well as patients of memory problems.

Additionally, in 2013, GPs will have the option of undertaking a new Directed Enhanced Service (DES). This will see them carrying out assessments and testing for dementia in those patients identified as 'at risk' who may be showing early signs of dementia.

Those considered to be at high risk of developing dementia include people with any of the following conditions: diabetes mellitus, cardiovascular disease including stroke and Transient Ischemic Attack (TIA), Parkinson's disease, a strong family history of dementia, mild cognitive impairment, high blood pressure, Down's Syndrome, or learning disabilities.

Some GPs have reported an increase in numbers presenting with Korsakoff's Syndrome with the increase in alcohol consumption in the UK. While not strictly speaking a dementia, people with this condition may experience loss of short-term memory.

Enabling people to be better able to manage their own wellbeing and health conditions is a focus of much of the work of the local public health departments and emerging Health and Wellbeing Boards, emphasising support to remain independent, future planning, and early interventions.

Case for Change

There is a need to increase the public awareness of the potential risk of dementia for those people who have diabetes, cardiovascular disease, Parkinson's disease, Mild Cognitive Impairment (MCI), high blood pressure, or learning disabilities and to increase the advice available.

People with Down's Syndrome are at a high risk of an aggressive form of dementia and do not fit into services designed for much older people.

Improvements to health promotion and preventative services will enable people to feel more able to find help and to look after their own health, reducing unnecessary risks, and resulting in people with dementia feeling less isolated.

There is international evidence that a five-year delay in the onset of dementia can result in a 49 per cent reduction in projected dementia prevalence[20] and reduce deaths directly attributable to dementia by 30,000 a year[21].

Early targeted support can result in a 23 per cent reduction in the need for institutional care[22].

> “I will be able to access advisory services as well as leisure options that will help me maintain good health and raise awareness of risk factors.”

Best Practice

A referral through the NHS Health Check scheme can allow people to access Solihull Health Trainers or Birmingham Community Navigators.

Define the Changed State

I will be able to access advisory services as well as leisure options that will help me maintain good health and raise awareness of risk factors.

I will be aware and feel able to live healthily to reduce my risk of developing dementia and delaying potential cognitive decline.

I will feel less socially isolated.

There will be high-quality accessible consistent information available within my community, and early healthy lifestyles messages will be promoted.

Key Actions

1. Promotion of principles of primary care Dementia DES (Directed Enhanced Services).
2. Ensure services are available for frail elderly, including those with early stages of dementia, giving them access to services that promote health and wellbeing and reduce social isolation.
3. Staff in long-term condition clinics will be trained to identify potential symptoms of early stage dementia.

PREVENTION AND HEALTH PROMOTION

3. Dementia-Friendly Communities

"I will live within a community that values, respects and supports me as an individual."

National Dementia Declaration – A Call to Action

"I still go out. I even do walks round the block, a nice good walk. Meeting people is lovely…sometimes I walk up that way to the shops... My life… It's what you make it, isn't it?"

Service user – Transitions

Background

The development of dementia-friendly communities is a key element of the programme of work put in place with the Prime Minister's Challenge on Dementia early in 2012. It focuses on developing communities where people will be aware of and understand more about dementia, and how they can help to support people in their community.

People with dementia and their carers will be encouraged to seek help and support, they will feel included and valued, be more independent, and have more choice and control.

Case for Change

People with dementia and their carers said they often felt discouraged and unsupported by their community, and excluded because of their condition. This, they said, made it difficult to live independently with choice and control over their life.

Best Practice

Solihull Metropolitan Borough Council has signed up to the Dementia Action Alliance as well as a number of organisations across Birmingham and Solihull. These include Heart of England NHS Foundation Trust, Touchwood Shopping Centre and Centro.

In Hampshire and Sheffield, people with dementia and their carers could easily identify which supermarkets they would go to for consistency of layout, signs, staff attitude and available help, even though getting there might involve a longer bus journey.

Define the Changed State

I will be able to find my way round my local area and be safe.

I will be able to access the local facilities that I am used to and where I am known (banks, shops, cafés, cinemas and post offices).
I will maintain my social networks and continue to feel I belong.

Key Actions

1. Development of community capacity building/small grant programmes.
2. Publicise 'Dementia Friends', 'Dementia Champions' and 'Dementia-Friendly Communities'.
3. To work with local groups, organisations and agencies to develop dementia alliances which will improve the lives of people with dementia.
4. Include early identification of dementia as a priority for health and social care services.

RECOGNITION AND IDENTIFICATION

1. Case for early detection

> *"My condition will be identified earlier, and referred on promptly for a specialist assessment."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"I felt it was important to know what was actually wrong with me. I mean, it might have been, at the time, I didn't understand it and, being depressed, I couldn't understand it, but I still feel I should have the opportunity to know."*
>
> **Dave age 45**
> **Rebekah Pratt and Heather Wilkinson (2001) Tell me the truth, London: Mental Health Foundation**

Background

Many people told us that they did not talk to their GP about their memory loss or other symptoms of dementia. Of those who had, many felt that their symptoms were not taken seriously. Often they were told that they had to expect memory loss as 'they were old'. Some had to ask many times before their GP would do anything. On the other hand, many GPs who were interviewed talked about there being no point in identifying if people had dementia because there was no cure, no services, and no treatment.

Fear of dementia is a significant concern in the elderly, but some of the same symptoms of memory loss can commonly occur also in normal ageing and depression. Or, can be a sign of other problems such as side effects of medication, infection and cancer. So an assessment may actually help to identify other conditions and these may be treatable.

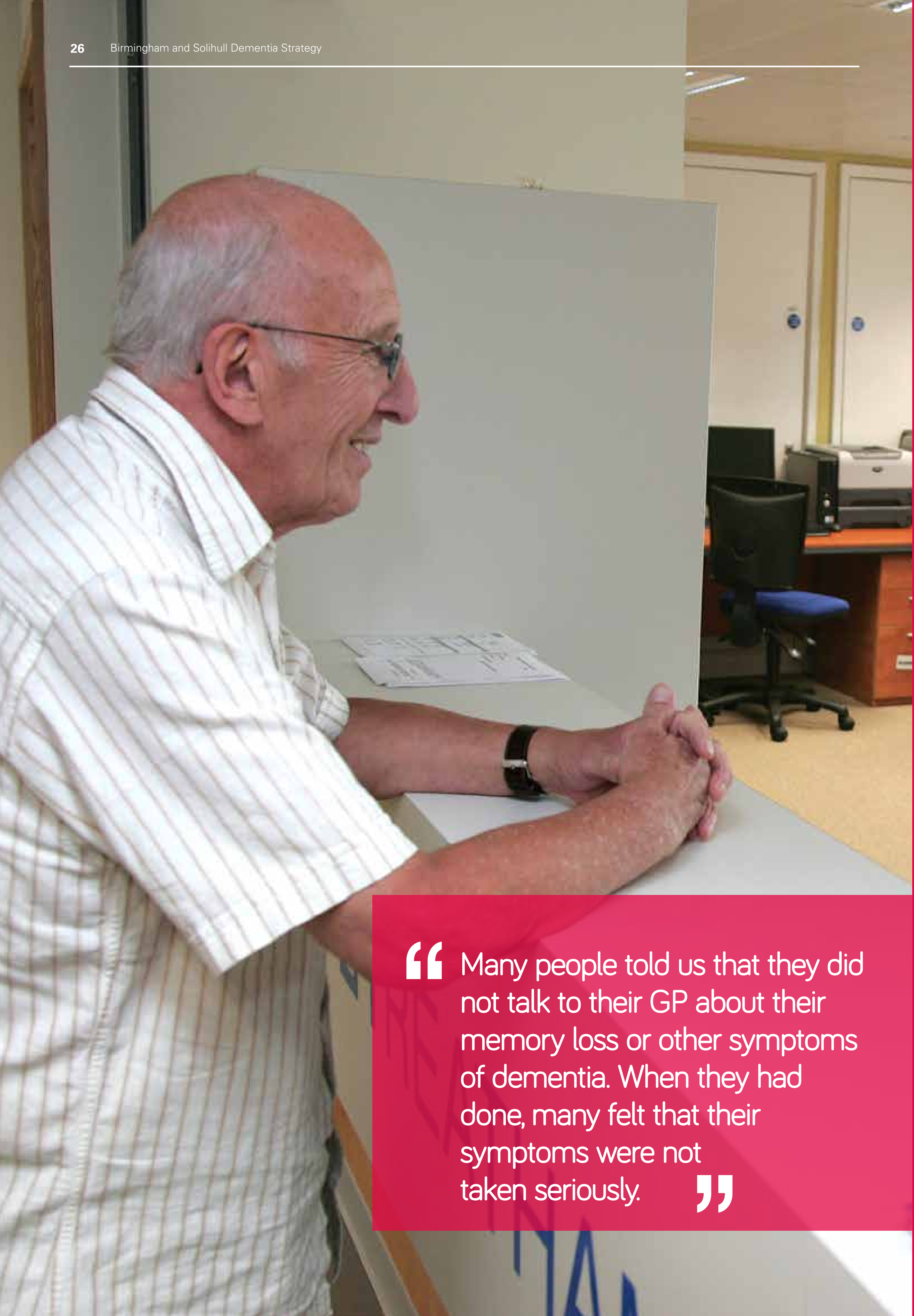
Recognition and identification in Birmingham and Solihull refers to the process by which non-specialists will identify people who might have dementia, exclude other conditions, and make appropriate onward referral to specialist assessment services.

The evidence shows that 'under-diagnosis' (of dementia) is the norm, with only 42 per cent of people in England having a formal diagnosis. The consistent view of those people with dementia and their carers who talked to us was that, while no-one wants dementia, people do want to know what is wrong with them so that they can move forward with their life. We do know that, currently, where there is a diagnosis, it often happens very late in the process of the disease, usually when there has been substantial cognitive decline that has impacted on the person's ability to carry out day-to-day activities.

Early diagnosis relies on early identification, i.e. recognition of the signs and symptoms, usually in primary care, leading to the exclusion of other conditions and then, in Birmingham and Solihull, a referral to Secondary Care for a specialist assessment.

Early recognition of individuals with learning disabilities can be difficult as they also have diverse needs that may include a variety of co-morbidities requiring difficult approaches to ensure optimal response to interventions.

The major benefit of an early diagnosis is that it helps people to get treatment and support, including planning, with their family and professionals, for their future. Undiagnosed dementia can pose a significant risk to both the person with dementia and their carers in that they may expose themselves to preventable ill health or harm – a common example would be through incorrect taking of medication.



> “Many people told us that they did not talk to their GP about their memory loss or other symptoms of dementia. When they had done, many felt that their symptoms were not taken seriously.”

There is a range of mental ability tests that can be used in primary care. Some GPs, however, have said that they are confused over which is the most appropriate for use.

Additionally, concerns have been raised about the appropriateness of some tests, particularly in cases where a person's first language may not be English. Certain test may not be the best approach for people with learning disabilities, or even where dementia is not typified by memory loss.

Case for Change

Across Birmingham and Solihull rates of diagnosis vary from 45 per cent for Solihull CCG, to 67 per cent for Birmingham South and Central CCG, with Birmingham CrossCity and Sandwell and West Birmingham achieving 46 per cent and 48 per cent respectively (compared with a national average of 46 per cent). A new national ambition is set at increasing the diagnosis rate in all areas to 67 per cent.

The Forget Me Not Report[42] identified significant resistance among GPs to diagnose dementia. This has been seen recently in public, professional discussion expressing scepticism about the national Directed Enhanced Service (DES) scheme for GPs targeted at identifying and screening patients at risk of dementia.

Some GPs felt there were gaps in services for people suffering from conditions such as alcohol-related dementias and rarer dementias.

There is evidence to support the benefits of early diagnosis, intervention and ongoing support. If dementia is diagnosed early enough medication can be used (for some dementias) to delay the progression of the disease. Apart from this there are a number of things that can be done to help people and improve their quality of life.

Best Practice

Figures show that Birmingham South Central Clinical Commissioning Group has achieved much higher diagnosis rates than national averages.

Define the Changed State

I will be aware of the early signs of dementia and understand the benefits of early diagnosis.

I will get a diagnosis earlier in my journey.

Key Actions

1. Agree a consistent referral pathway for Primary Care.
2. Set targets for increasing diagnosis rates so that professionals recognise its importance.

To find out more information or to see the video visit **www.vimeo.com/61050579.** To access the paper copy of 'Connected Compassionate Communities' **Click here**

> “A person's first contact with a GP has the potential to determine the course of the rest of their illness.”

RECOGNITION AND IDENTIFICATION

2. Case Finding/Making Every Contact Count

> *"We will make every contact count with our patients to identify people with early signs or at risk of dementia to ensure they have the opportunity to be fully assessed at the earliest opportunity."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"…and gradually things got worse and it became more and more difficult to get people to pay attention, it seemed that… the doctors just didn't seem to know what to do and you're kind of left to your own devices, just staggering along."*
>
> **Carer talking about getting a diagnosis for his wife**

Background

The findings of the All-Party Parliamentary Group on Dementia[43] identified that a key barrier to early diagnosis was a lack of understanding of the symptoms of dementia. People we spoke to felt that this could be improved through campaigns and awareness raising in primary care, that would ensure that symptoms were picked up and risks identified as early as possible.

Additionally, identification of dementia (and other mental health issues) can be subject to different cultural interpretations and may be subject to greater stigma, leading to an even greater unwillingness by some groups to approach GPs.

We know that some groups have a higher risk of developing dementia. These include:

» People over 50 years of age with learning disabilities
» People over 35 years old with Down's Syndrome
» People over 60 years old with coronary vascular disease, pulmonary vascular disease or diabetes
» People with Parkinson's disease
» People who consume high levels of alcohol over a long period of time
» Older people, as risk increases with age
» People with risks associated with known genetic/familial history.

Advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities and so understanding the effects of ageing among this group has become increasingly important. People with a learning disability are at greater risk of developing dementia at a younger age. This is particularly the case for people with Down's Syndrome – one in three develops dementia in their 50s. When people with Down's Syndrome develop dementia, this is usually due to Alzheimer's disease. There is, however, a growing awareness that people with Down's Syndrome can develop other forms of dementia. It is recommended that there is an earlier stage in the assessment pathway for dementia in people with learning disabilities, this would be an early screening to provide a clear picture of their skills and abilities for later comparison.

Prisoners aged over 60 are the fastest growing age group in prison. This increase in numbers is largely due to longer sentences. It is predicted that the number of older prisoners will continue to increase unless there are major changes in sentencing trends, and we need to make sure access to memory assessment services and follow-up support is in place where needed[25].

Case for Change

People are not always referred for a specialist assessment when this would lead to a clear diagnosis.

Best Practice

Work is under way with Public Health and Birmingham and Solihull Mental Health Foundation Trust in Birmingham to support primary care to include dementia in the NHS Health Check.

Birmingham Learning Disabilities Specialist Health Service work alongside the Community Learning Disabilities team to provide specialist services for people with learning disabilities and dementia.

Define the Changed State

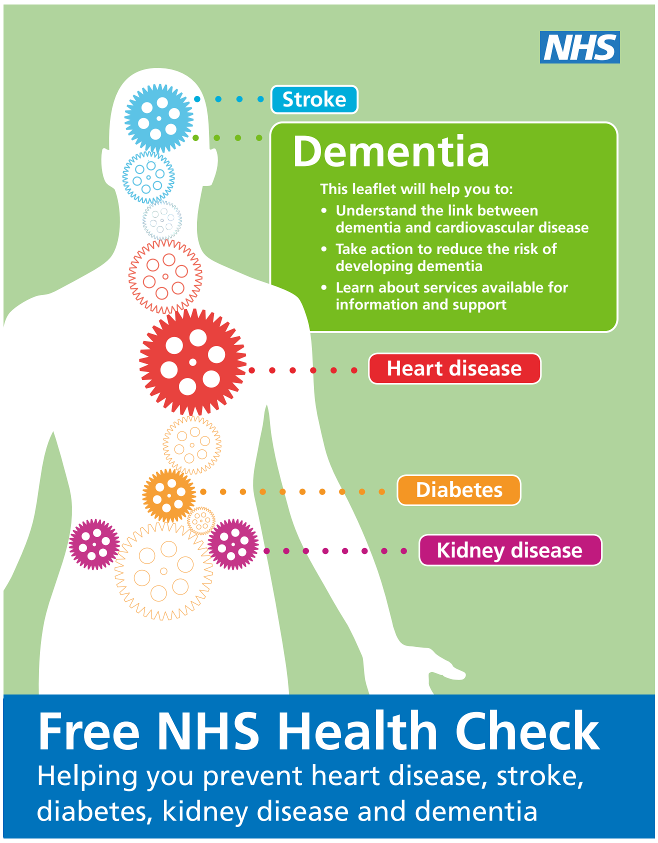
My GP will be proactive in identifying what is wrong with me when I am concerned that I may have dementia.

My cognitive state will be monitored in Primary Care or other appropriate services if I am at risk of dementia, referring on if there are significant changes.

I will be able to have my symptoms investigated appropriately through other services that I might use more regularly such as learning disabilities services, prison, or alcohol services.

Key Actions

1. To ensure that professionals across all sectors of health and social care are aware of the early signs of dementia and feel confident to use the dementia screening tool and know where/how to signpost/refer appropriately.
2. Ensure that professionals working in specialities with higher dementia risk factors are regularly screening patients for dementia.
3. To ensure access to high quality learning and support opportunities in dementia for professionals including those who work within learning disabilities, substance misuse services and prison staff.



Dementia

This leaflet will help you to:

- Understand the link between dementia and cardiovascular disease
- Take action to reduce the risk of developing dementia
- Learn about services available for information and support

Free NHS Health Check

Helping you prevent heart disease, stroke, diabetes, kidney disease and dementia

> "The findings of the All-Party Parliamentary Group on Dementia identified that a key barrier to early diagnosis was a lack of understanding of the symptoms of dementia."

RECOGNITION AND IDENTIFICATION

3. Recognition and Referral including in acute hospital settings

> *"All patients identified as being at risk should have access to an assessment of their cognitive state and referral onwards for specialist assessment if appropriate."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"In fact, it seems, looking back, that there was never any continuity between the phases, people seemed to be doing their own little thing, their own specialised medical knowledge...... and finally she got handed into the system properly, that whole first process took about 5 years. .... It's hard to explain, but it all seemed directionless and most uninspiring."*
>
> **Carer talking about getting a diagnosis for his wife**

Background

Cognitive tests or cognition 'tools' that identify the level of cognitive decline and whether it requires further assessment or indicates an alternative diagnosis, can take as little as three minutes to perform. They can be used by clinicians and non-clinicians once they are trained. The tests are used in both acute and primary care settings. Other tests will also be used in order to rule out conditions that might have some of the same symptoms, for example, depression.

People with some types of dementia will display personality changes and executive dysfunction but may have normal cognitive test results. These people will require further testing/assessment through the specialist services before a diagnosis can be given.

Often, the first time symptoms might be noticed and explored (particularly for people who live on their own) is when someone is admitted into a general hospital for care. Knowing that someone has dementia could make a lot of difference to the way they are managed in a hospital setting.

In response to this, a mental health liaison service has been set up in acute hospitals across Birmingham and Solihull.

The Rapid Assessment, Interface and Discharge service (RAID) helps with the recognition of mental health problems, including dementia. It provides a specialist service that helps acute staff to identify people who possibly have dementia, and supports those staff, with training and advice, so that they are able to manage the person's care more effectively.

Also, in 2013, hospitals committed to asking people over 75, who are admitted as an emergency, if they have had memory problems. This will help them identify people who may have dementia and may need further tests.

Case for Change

Many people spoke about the difficulties they had encountered once they (or someone else) had noticed symptoms of dementia, with finding out more about it and getting a clear diagnosis, particularly if their healthcare professional was unable to advise them.

> “Knowing that someone has dementia could make a lot of difference to the way they are managed in a hospital setting.”

Best Practice

The RAID (Rapid, Assessment, Interface and Discharge) service has now been rolled out across all the acute hospitals in Birmingham and Solihull.

Define the Changed State

I, and my carer, will already have recognised a problem by the time it reaches specialist assessment.

I know that there will be consistency in my assessment in all areas of my care and that I will not be continually asked the same questions.

I will be able to easily find out about local dementia services and dementia-friendly activities.

Key Actions

GPs and other professionals to be proactive in identifying high-risk groups, including excessive and long-term alcohol use and learning disabilities.

> “Cognitive tests or cognition ‘tools’ that identify the level of cognitive decline and whether it requires further assessment or indicates an alternative diagnosis, can take as little as three minutes to perform.”

RECOGNITION AND IDENTIFICATION

4. Mild Cognitive Impairment (MCI) and Subjective Cognitive Impairment (SCI)

> *"If I have mild problems with my memory then I will be given assistance to understand the problem and help to improve my cognitive skills."*
>
> **National Dementia Declaration – A Call to Action**

Background

Around 20 per cent of people who have symptoms of memory loss and undergo a specialist memory assessment will be diagnosed with mild or subjective cognitive impairment. We know that around 45 per cent of people who are diagnosed with mild cognitive impairment will go on to develop a dementia within three years of their Mild Cognitive Impairment (MCI) diagnosis, but it is not possible to predict who will be affected.

A number of the people we spoke to felt that this diagnosis left them 'in limbo' and unsure about their future.

Mild Cognitive Impairment is a clinical state where people have impairment of cognition that is not significant enough to be diagnosed as dementia.

Subjective Cognitive Impairment is a clinical state where the patient experiences problems with their memory but cognitive testing is normal.

There is no evidence of any effective interventions for people with Mild Cognitive Impairment that will prevent them developing dementia, however, most specialists advise detailed explanation of the diagnosis and prognosis. In addition, most experts would encourage maintaining mental skills through encouraging a healthy lifestyle and using brain exercises.

Case for Change

Different models exist for managing and following up Mild Cognitive Impairment locally and GPs are often confused about what to do as follow-up.

Define the Changed State

If I have Mild Cognitive Impairment my family and I will be equipped to identify further changes in my memory and functioning and be able to go back to services for further advice, support and action.

If diagnosed with Mild Cognitive Impairment I will feel encouraged and supported to stay healthy.

Key Actions

Agree a common approach to Mild Cognitive Impairment assessment and intervention, with support offered to primary care by specialist memory assessment services where required.

ASSESSMENT, DIAGNOSIS AND PLANNING FOR THE FUTURE

1. Assessment and Diagnosis

"If I need an assessment for my memory and thinking, it will be done in the right way, at the right time, by the right person."

National Dementia Declaration – A Call to Action

"He said: 'Well it's patently obvious what's wrong with your wife; everybody knows what's wrong with your wife – don't you?' And he got quite nasty and I said: 'No, we don't'. He said: 'Well she has FTD.' I said: 'what the hell is FTD when it's about?' He said: 'You don't know what FTD is?' I said: 'No'. He said: 'Nobody's ever said Frontal Temporal Dementia to you?' and I said: 'No'. He said: 'Well that's what your wife's got', and he really lashed into us and he reduced my wife to absolute tears. And we both came out of there totally distraught...it had taken seven years of back and forth and several sorts of tests before somebody had socked us between the eyes and out of the blue with this diagnosis."

A carer talking about how the diagnosis was finally given

Background

People with dementia and their carers/families have told us they want a consistent and timely assessment process where things are made clear to them in a way that they can understand. Family members have told us that they would like their needs taken into consideration when planning for the future.

In Birmingham and Solihull, primary care or even better GPs plays a key role in recognising and identifying the symptoms of dementia and referring the person on to specialist memory assessment services. There, they have a more detailed and comprehensive assessment that may take some time, depending on what is required. This is because NICE (the National Institute for Health and Care Excellence) requires a formal diagnosis of dementia to be made only after specialist assessment by, or under the supervision of, a dementia specialist (Old Age Psychiatrist, Neurologist or GP with special interest)[26].

In 2012 we restructured memory assessment and community mental health team services across Birmingham to increase capacity and ensure consistent governance. Local points of access were also introduced to make referral easier.

Assessment for dementia in adults with learning disabilities needs to be carried out differently. It should reflect the fact that people with learning disabilities may never have acquired the same set of cognitive skills as others. Additionally the inital presentation of dementia may cause changes in behaviour rather than memory loss. Because of this,there is the need for specialist diagnostic services and tools to support the assessment process.

The memory assessment services across Birmingham and Solihull are currently in the process of accreditation through the Memory Services National Accreditation Programme (MSNAP).

All clinical commissioning groups will now have access to local information about diagnosis rates through the newly issued Dementia Prevalence Calculator and resource calculator, which will be a key tool for them to set targets and to monitor achievement around numbers with a diagnosis.

Since people with dementia have been identified as at increased risk of falls, services carrying out memory assessments are encouraged to complete a falls assessment at an early stage.

> People with dementia and their carers/families have told us they want a consistent and timely assessment process service where things are made clear to them in a way that they can understand.

Case for Change

People with dementia and their carers and family members do not always get the same level of services after diagnosis across Birmingham and Solihull.

Not everyone gets told their diagnosis in a way that they can understand and they are not always given enough time to digest what they have been told before being discharged back to their GP.

Not all health staff undertaking this work have the same level of skills, experience and understanding.

The assessment process – 'one size fits all' – does not work for everybody.

It can be difficult to access mental health support while also undertaking a memory assessment.

People are not always clear about what the assessment may include or how long it can take.

Best Practice

People assessed in local memory assessment services will normally see the same practitioner throughout the assessment and diagnostic process.

The Promoting Independence Team in Solihull provides a timely six-week programme of reablement support to people in the early stages of dementia.

The Birmingham Learning Disabilities specialist health service provides diagnosis and assessment services which comply with NICE guidance and associated quality standards.

Define the Changed State

If I need to know what is happening to my memory and thinking, I will get referred to a specialist service, get an appointment quickly with someone who knows what they are talking about and will be told what is wrong with me in a way that I can understand.

I will be able to be seen by the same person and not have to repeat my story over and over again to different people.

I will have been prepared for any difficult news I might have to hear and asked who else I might want to be with me when I am told.

I will be able to choose whether I want to know what my diagnosis is.

I will be helped to explain to my family what is happening to me, and we will all get the right support.

I will be able to go through the whole process at my own pace.

I will always be asked what I want even when I find it difficult to answer.

I know that I will be treated with compassion, dignity and respect by all those who work with me.

Key Actions

1. Agree clinical pathways between primary and secondary care.
2. Ensure external monitoring of Memory Services National Accreditation Programme (MSNAP) is in place.
3. Training for GPs to cover learning disabilities and dementia.

ASSESSMENT, DIAGNOSIS AND PLANNING FOR THE FUTURE

2. Early Support and Treatment for Patients and Carers/Families

"If I am told I have dementia I will be given time to ask questions, get the information and support my family and I need, and receive any treatment and support I can have as soon as I am ready."

National Dementia Declaration – A Call to Action

"I was told my diagnosis but I did not really understand what it meant. My wife was even more confused than I was. We went home and sat there in a bit of a daze – what do we do now, we thought. I was not sure what it really meant and had not been told if there was anyone I could ask. Lucky for us my son was good with computers and he was able to find some information, he also asked my doctor if there was any medication that could help me. It was a very worrying time for all of us."

A person with dementia talking about what happened after he was given the diagnosis

Background

In Birmingham and Solihull memory assessment services include specialist advice around the diagnosis and its implications, management and support options and a referral into the Dementia Adviser service (commissioned through Alzheimer's Society). This will follow up if the person with dementia does not feel able to use the service immediately following diagnosis.

Those we spoke to told us that there is a need for improvement in the provision of information and advice and the quality of support for people following diagnosis across the area. This was reiterated at a national level in The Prime Minister's Challenge on Dementia[8].

People told us that they wanted to know:

- What help was available and how they could get the support they needed
- That they could access whatever treatments were available as soon as they could following their diagnosis, without having to repeat all they had just gone through
- What support or treatment they could expect for themselves and the people who mattered to them.
- What provision is made for people with learning disabilities whose family and paid carers need accessible information at different stages and as new symptoms appear. This will include ready and flexible advice on the management of behaviours and symptoms.

A critical factor appeared to be where and when the diagnosis was made, as the dementia adviser service can only be accessed through memory assessment services (which have only been in place for three years).

Additionally, if a diagnosis was made through the memory assessment service, carers would be offered an assessment of emotional, psychological and social needs and. If accepted, they would be offered a care plan that would include appropriate interventions.

Case for Change

Good support and treatment is offered in a number of areas but is not happening everywhere. The level of support given pre- and post-diagnosis can often depend on where the diagnosis is made, particularly whether they have had access to dementia adviser services following diagnosis.

People are often not clear on what they can expect and where they can go for help, and signposting is inconsistent.

The needs of others involved with the person diagnosed are not always recognised.

GPs are not always kept up to date by other services involved with their patient.

Fewer than a third of GPs believed they had received sufficient training to diagnose and manage dementia[29].

There can be long waits for treatment.

Agencies do not work collaboratively enough to make it easier for people with dementia and families to find the support they need.

Staff working in dementia services may need more training on how to give culturally acceptable care and support to people from a range of backgrounds with dementia.

Best Practice

Personalised support plans developed by senior practitioners in the memory assessment services (following a diagnosis) across Birmingham and Solihull, include access to specialist, evidence-based interventions such as Cognitive Stimulation Therapy and Self Management Programme.

Services such as the Dementia Advisers and DISC (Dementia Information and Support for Carers) provide support to people with dementia and their carers following a diagnosis.

Define the Changed State

I have a key role to play in my own care and support following assessment and diagnosis, and my carer will also have the opportunity to be involved.

My carer will be supported to care for me if and when I need help. I will get treatments and interventions that help me quickly following my diagnosis.

Key Actions

1. Ensure that there is consistent access to post-diagnosis support, including access to the appropriate practitioners to develop support plans, wherever and through whatever route the person is diagnosed.
2. Ensure people newly diagnosed with dementia are offered treatment where clinically appropriate in a timely way.
3. Carers to be offered an assessment of their own emotional, physical and social needs and a care plan developed with them which will identify appropriate interventions and support to assist them with their role as a carer.

> "There is a need for improvement in the provision of information and advice and the quality of support for people following diagnosis across the area."

LIVING WELL WITH DEMENTIA

1. Living Well (community inclusion, feeling valued, living normally)

"I live in an enabling and supportive environment where I feel valued and understood."

National Dementia Declaration – A Call to Action

"So it's a bit scary, but I'm lucky because I've got lovely friends and they're all there for me, sort of enclosing me in this. My friends, they're brilliant. They'll come over to see me and they'll grab hold of me and they'll say come on, we're going out, and I think that's the best thing you can do."

A person with dementia talking about living well

Background

In Birmingham and Solihull our own local work with people with dementia and their carers has provided us with a wealth of information about what they need in order to be able to live well with dementia. Much of this is reinforced by the National Dementia Declaration[5].

Locally, people with dementia and their carers told us that:

- A diagnosis of dementia could result in them becoming isolated and lonely as family and friends struggled to come to terms with the illness and detached themselves
- They often found it difficult to participate in normal community-based activities as other people struggled to accept and be comfortable around people with dementia
- For those impacted by dementia while still of working age, employers often struggled to accommodate changing needs
- Where they found services and support that made them feel at ease it had a significant impact on their wider wellbeing
- Where they had received good help and support post-diagnosis, for example through a dementia adviser, they were better able to plan their journey with dementia and have the confidence to live as normal a life as possible, accessing wider community-based services when the need arose
- They valued peer support groups that enabled them to mix in a non-judgemental environment, form new friendships, and develop a supportive social network.

Case for Change

Many people with dementia do not feel a valued part of their community.

There is a lack of community-based activities for people with dementia and their carers.

Different communities may have differing views about what they need to live well with dementia.

Best Practice

Dementia support workers across Birmingham and Solihull are enabling and empowering people with dementia and their carers to access community-based services, supporting initial visits if needed.

> “Dementia support workers across Birmingham and Solihull are enabling and empowering people with dementia and their carers to access community-based services, supporting initial visits if needed.”

Define the Changed State

I will feel less stigma associated with dementia and an increased sense of inclusion and wellbeing.

I will be able to easily use more community services.

The services I use will be based on meeting my needs and those of my carer and family.

Key Actions

1. Assist people with dementia and their family/carers to access support to maintain quality of life.
2. Engage people with dementia and their family/carers in commissioning decisions.
3. Work with local communities and encourage them to be more visibly welcoming to people with dementia.

To see our video visit: **www.vimeo.com/61029795.** To access the paper copy of ‘Connected Compassionate Communities’ **Click here**

LIVING WELL WITH DEMENTIA

2. Planning for the future and personalisation

"I have support that helps me live my life."

National Dementia Declaration – A Call to Action

"…many people have said: 'well I went years without a diagnosis', so get a diagnosis and then make contact with the groups that can help you through this journey with dementia. Don't try and isolate yourself. I suppose if you're of a very large close-knit family, you're going to be in a different position to me, but I am not, so I do need other people, I need contacts I can go to."

Carer, talking about what advice she would give to others

Background

People with dementia, families and carers, are highly complimentary towards staff and services that offer information, advice and support, such as Alzheimer's Society and DISC (Dementia Information and Support for Carers). This praise, however, is often set against how long it took to find out about the support, and how difficult life was before they could access it. In response, we have aimed to ensure that, wherever possible, people who are diagnosed with dementia are linked directly into the dementia adviser service at the time of diagnosis.

Often, without this, people with dementia and their carers do not know how and where to access support and try to cope until they reach a point of crisis. This impacts on their wellbeing and often puts a strain on statutory services.

People with dementia and their carers tell us that they want to live a normal life, yet their experiences of care commissioned for them is often regimented, institutionalised, and far from normal. Several people reflected that care often revolved solely around meals and bingo.

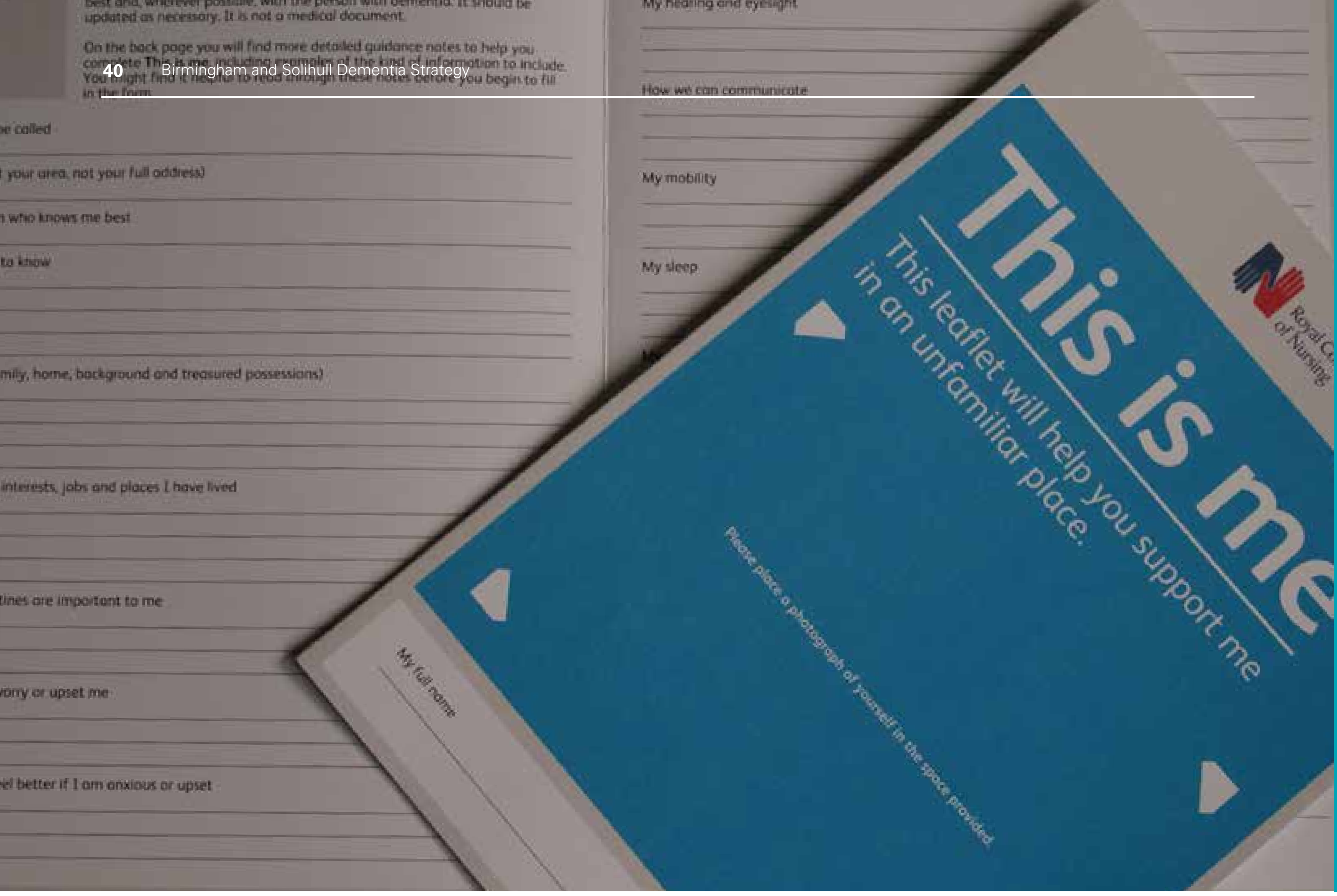
Many service users felt it was important that the advice they received helped them to understand risk and stay safe and that it needed to include planning for next steps. This currently tended to come through the dementia advisers, dementia support workers, and other specialist services.

Case for change

People with dementia and their carers need to know where to access support and that it is available in a timely fashion and as early in their journey with dementia as possible. This is particularly relevant when things change or where they feel at a point of crisis. Dementia is a long-term condition that requires advice and support at the start and to be available throughout the journey. However, in the past 20 years, social care and support services have been designed more and more to provide short-term interventions.

Often the support required at any one time can be 'low-level' but important, for example, being put in touch with a peer support group or dementia café when lonely and isolated, advice on how to ask for a break from caring, support to stay in work, or which benefits can be claimed. Further on in the dementia journey, it might be that a family member contacts the GP to say that a person is becoming distressed or the sleep pattern is disturbed, and more specialist help is needed.

Some people who have had a diagnosis of dementia have not had access to the type of specialist advice and information that a dementia adviser-type of service can provide. This can be due to either an assessment outside the memory assessment service or inconsistent access to the service. This is important in order to link them in to what else there is available, including the dementia support worker service, which can provide longer term support.



Best practice

Many providers now use 'This is me'[30] – a tool for people with dementia receiving professional care developed by Alzheimer's Society. This allows the Alzheimer's Society people with dementia to tell staff about their needs, preferences, likes, dislikes and interests, enabling health and social care professionals to see the person as an individual and deliver care that is tailored specifically to the person's needs.

Both Birmingham City Council and Solihull Metropolitan Borough Council fund dementia support workers through the Alzheimer's Society to support people who are being diagnosed or are already diagnosed, offering individual support to the person with dementia OR the carer, with a focus on improving quality of life and avoiding crises.

Define the Changed State

I will have an assessment and an ongoing personalised care/support plan, agreed across health and social care, that identifies a named care co-ordinator and addresses my individual needs. NICE quality standard for dementia

I will be offered support to complete life diaries.

I will be offered support to write future care plans.

If I am eligible I will be offered and supported to have a personalised care budget.

I will be offered services that help me plan for the future and access services in a way that suits me.

Key Actions

1. All people with dementia to have access to support to offer help and guidance with navigating care and other services.
2. Improve relationship between dementia support services and mental health services.
3. People with dementia to be able to create their own life diary and to be involved in ongoing care planning, including advanced care planning.
4. Commission services taking into account dementia is a long-term condition and ensuring service provision has an appropriately wide range of options to suit the needs of individuals.

LIVING WELL WITH DEMENTIA

3. Support along the journey – Information, signposting, education, peer support, easy access in a crisis

> *"I have the knowledge and know-how to get what I need."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"You go along with it. It's something that it comes and it goes and you can still carry on living, you know, which is what we have to be thankful for! … I mean, at the end of the day there's absolutely nothing you can do about it but carry on enjoying life."*
>
> **Service user talking about living well with dementia**

Background

Feedback from service users and their carers and families told us that, following a diagnosis, access to services such as dementia advisers had been invaluable in linking them into information and support services that could help them. Data shows, however, that only around 60 per cent of newly diagnosed cases have historically accessed the dementia adviser service. Also, as the dementia adviser service has only been in existence for three years, there are significant numbers of people who have never received appropriate post-diagnosis support. People were also clear that they wanted a person-centred problem-solving approach to the issues they faced.

The dementia adviser service is seen as critical in helping people come to terms with the diagnosis and supporting people with dementia and their carers in planning and navigating their journey with dementia. There are particular issues that arise where people feel unable to accept or acknowledge the diagnosis and people may be more likely to 'fall through' the net in current services in these cases. We know there are lessons we can learn from palliative care approaches here.

The emotional and spiritual needs of people with dementia and their carers are often not considered at an early stage in their journey.

Case for Change

Access to specialist advice is inconsistent.

Access to specialist advice is important throughout the disease as requirements change.

Many carers are unaware of any support available to them in a crisis.

Best Practice

Birmingham and Solihull Mental Health Foundation Trust is working in collaboration with partners such as Apna Ghar (a day service for Asian elders) to support service users, helping to deliver support such as Cognitive Stimulation Therapy and Psycho Education Groups.

Birmingham City Council provides a Carers' Emergency Response Service (CERS). This service offers carers assistance in planning for emergencies and providing emergency respite care when needed.

The Growing Older with Learning Disabilities sub-group of the Birmingham Learning Disabilities Partnership Board has produced a range of resources around dementia aimed at people with learning disabilities.

> “Nationally, 800,000 people in the UK live with Alzheimer’s and other dementias. This includes more than 17,000 younger people and 11,500 people with dementia from black and minority ethnic groups in the UK.”

Define the Changed State

I will be able to access specialist dementia adviser-type services regardless of where I have been diagnosed.

My carer and I will have access to information and support throughout our journey.

My GP will refer me for assessment,and supply information and support to both my carers and I.

I will have access to a holistic assessment of all my needs and be supported to create a personal plan for my care, including how I will access specialist care in a crisis.

Key Actions

1. Ensure that all those who have had, or are receiving, a diagnosis are able to access specialist dementia advice and information.
2. Ensure that all those with a diagnosis of dementia and their carers are able to access ongoing support.
3. Increased access to carer education, whether through formal courses, a dementia adviser or attendance at structured support groups such as dementia cafés.
4. Ensure support is available for people who are unable to accept or acknowledge the impact of their diagnosis.

LIVING WELL WITH DEMENTIA

4. Staying safe and secure at home – Financial, legal and practical support Telecare/assistive technology/home adaptations/home support – domiciliary and nursing, re-enablement

> *"I have personal choice and control or influence over decisions about me."*
>
> **National Dementia Declaration – A Call to Action**

Background

People told us how important it was to them to be able to access the right kind of specialist information and support after a diagnosis. This can include a range of different types of information, including about the services that are available for them.

The support and care needs of younger people with dementia tend to be very different from those of older people (over 65s). This also applies to those with learning disabilities and dementia.

Increasing numbers of people with dementia are living on their own, often far from any family support. This can make it particularly difficult to ensure that they are safe, secure and independent.

The first step to access financial and practical support is often to have a needs assessment by a social worker. However, financial issues such as power of attorney, wills, allowances and debt advice may be handled better by other agencies.

People with dementia are at higher risk of falls. There are a range of very simple options that can be employed that can reduce environmental hazards and ensure environmental risks are minimised.

If help and support is needed, a care package may be put in place. For this to be possible the person will also need to have a financial assessment to see if they qualify for financial help.

If the person qualifies for financial help, in other words, if they have 'substantial' or 'critical' needs, they may be provided with the services for themselves or be able to choose to have an Individual Budget (IB)/direct payment and use the money they receive to arrange their own support or services.

Birmingham City Council provides an appointee and Court Deputy Service that can look after the finances of anyone who finds it difficult to manage their affairs because of dementia. A similar service is available in other areas. Solihull Metropolitan Borough Council also funds advocacy support through the Alzheimer's Society.

Telecare and Assistive Technology – This is a developing service that can help individuals remain independent at home. There are a lot of different types of equipment available that can be used to detect emergencies or provide alerts to vulnerable people, their relatives or carers, for example, to take medication. These systems can also track people's movements to assist with monitoring the general health and wellbeing of an individual.

There are many other developments in terms of assistive technology that can be bought or provided as part of a care package that may make living in the person’s own home more practical, as well as common home adaptations.

Reablement – Both Birmingham and Solihull councils provide ‘reablement’ services to encourage, build confidence, help regain self-care skills and give tailored help to enable people to remain as independent as possible following an illness, an operation, or in later life. It is short-term (up to six weeks).

Home Support (domiciliary and nursing) – Social workers can provide information on services provided or arranged by the councils and on other supports, including local community facilities, housing facilities and equipment. Information is also available from a number of other sources including ‘My Care in Birmingham’ – a city council website.

Social care services can include help at home with personal care activities such as washing, dressing, feeding, toileting, or domiciliary care such as help with day-to-day tasks such as shopping or cleaning. Information is available on domiciliary care (home support) services through local authorities. There may be a charge for these services.

Provision of nursing support (if publicly funded) is usually through NHS Continuing Health Care (CHC). This is a package of continuing care provided outside hospital, arranged and funded by the NHS, for people with ongoing healthcare needs. Eligible people can receive NHS continuing healthcare in any setting, including in their own home or in a care home. This type of provision is free to the recipient and not needs assessed.

In the future, those entitled to continuing healthcare will be able to request a Personal Health Budget and can use this to purchase care.

Case for Change

Encouraging people affected by dementia to plan for the future and address their financial, legal and future care needs helps to reduce stress at later stages in the journey. Access to services, however, can be ‘hit and miss’ unless people are linked in to support services.

Providing access to support to keep people well, safe and independent in their own home will directly reduce the demand on statutory services, e.g. reduced admissions to hospitals. Also, in preventing carer breakdown and the indirect impact that this has on support services.

Best Practice

Solihull Virtual Ward is a service that supports people who are assessed as at a high risk of admission to hospital. The team is able to provide physical health interventions in the person’s own home that would previously have had to be done in hospital. It was extended in 2012 to take people with dementia.

The Alzheimer’s Society has arranged free legal advice sessions for carers in some areas.

Define the Changed State

My carer and I will be encouraged to plan for our futures and to address any financial and legal matters as early as possible once I have received the diagnosis.

I will be provided with access/ signposted to services and support that will help me to stay well, safe and independent in my own home.

Key Actions

1. Ensure ‘joined up’ assessments between health and social care.
2. Ensure access to reablement services.
3. Identify other non-dementia specialist services that could support people who have dementia with other aspects of their health and social care needs.

LIVING WELL WITH DEMENTIA

5. Safeguarding

Safeguarding is everyone's business

It is important to recognise that people with dementia may be vulnerable and at risk of abuse and neglect. The largest proportion of abuse happens in people's homes, but can happen wherever they live. Unintentional abuse can occur particularly where there is carer stress.

Abuse and neglect can take many different forms including physical, medical or emotional neglect, physical or psychological abuse, financial or sexual abuse. There is evidence to show that abuse is higher than average among people with dementia and that people with dementia can be particularly vulnerable to abuse . Dementia can make it harder to detect when abuse is taking place:

» People may find it difficult to talk about their experience of abuse.
» They may worry that they will not be believed if they speak out about abuse
» They may appear to be an 'easy target' for abuse because they do not have the capacity to understand what they are being told to do or the cognitive ability to remember what has happened to them.
» Many common behavioural reactions to abuse, such as withdrawal from communication or wanting other people present all the time, can also be symptoms of dementia.

Additionally there are particular issues around mental capacity for people with dementia (ref. www.alzheimers.org.uk)

The Government's policy objective continues to be to prevent and reduce the risk of significant harm to adults from abuse or other types of exploitation, whilst supporting individuals in maintaining control over their lives and in making informed choices without coercion.

The Government believes that safeguarding is everybody's business, with communities playing a part in preventing, identifying and reporting neglect and abuse and having measures in place locally to protect those least able to protect themselves.

Case For Change

New guidance issued nationally in May 2013 highlights the importance of prevention. Prevention of harm is better than investigating harm people have experienced, after the event. This guidance incorporates a number of key principles:

Empowerment - the presumption of person led decisions and informed consent

Prevention - it is better to take action before the harm occurs

Proportionality - the proportionate and least intrusive response appropriate to the risk presented is best

Protection - support and representation for those in greatest need is critical

> "Abuse and neglect can take many different forms including physical, medical or emotional neglect, physical or psychological abuse, financial or sexual abuse."

Partnership - communities have a part to play in preventing, detecting and reporting neglect and abuse

Accountability - accountability and transparency are required in delivering safeguarding.

Best Practice

Alerts can be made via Birmingham City Council and Solihull Metropolitan Borough Council. More information is available on the Birmingham Safeguarding Adults Board website (www.bsab.org) and for Solihull (www.solihull.gov.uk/adultabuse).

Define The Changed State

Professionals help me to plan ahead and manage the risks that are important to me.

People and services understand me - recognising and respecting what I could do and what I needed help with.

LIVING WELL WITH DEMENTIA

6. Active therapies, community assets

> *"I have a sense of belonging and of being a valued part of family, community and civic life."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"Well, I don't go out much unless I go out with my wife… I think the world of her, that's all I can say – I rely on her too much now. You know, that's all I can say."*
>
> **Person with dementia – Transition project**

Background

People with dementia and their carers identified the opportunity to meet people in a similar position as important to them, but many spoke of difficulties in finding these opportunities. Peer support could be just the provision of social activities but can extend to crisis support and practical help.

Active therapies that were sought by the people we talked to included a number that would have a positive effect on the condition of people with dementia. It could range from doing a word search puzzle to a trip to the cinema, the opportunity to go for a walk, gardening, and meeting friends for lunch in a local café. All those things that people without dementia take for granted as the rich texture of living a normal life.

The dementia adviser service is seen as key to providing information about, and signposting to, active therapies and community assets. These include Memory Cafés (peer support groups for people in the early stages of dementia) and Dementia Cafés (peer support groups for people with dementia and their carers). These are funded by the local authorities in Birmingham and Solihull and provided by the Alzheimer's Society in a number of locations. Additionally, activities such as 'Singing for the Brain' also offer therapeutic sessions to people with dementia and their carers.

Case for Change

We know a lot of community active therapy opportunities exist but they are not effectively mapped and there is no consistent way of sharing this information with those who might benefit most from them.

Best Practice

The Extra Care Charitable Trust has developed two out of an expected five retirement villages across Birmingham offering sheltered accommodation with a focus on community and a number of innovative projects looking at improving the health and wellbeing of residents.

Monthly Tea Dances are offered by Age Concern in Solihull. These are popular with people with dementia.

Define the Changed State

I will be able to access a broad range of activities that enables me to get support from others and keeps me both mentally and physically well.

As a person with dementia I will be able to access peer support services without needing my carer and talk openly about dementia and continue to access learning and social opportunities.

A comprehensive directory of services/active therapies will be available to me and my carer in a format I can use.

I will have access to support services, irrespective of my cultural background, and these will be culturally appropriate.

Key Actions

1. To actively work with council and community provided neighbourhood services to ensure that their services are accessible to people with dementia.
2. To develop local area service directories which will provide information to people with dementia and their carers about what is available in the local area that is dementia friendly.
3. To offer training and support to groups who are keen to open up their activities to people with dementia.

LIVING WELL WITH DEMENTIA

7. The Right Medication

> *"I will have access to medication that helps me without harm."*
>
> **National Dementia Declaration – A Call to Action**

Background

Many people with dementia have found that access to so called 'anti-dementia' drugs can make a huge difference to the quality of their lives. There is evidence to show that these medicines, which are available for some forms of dementia, can slow progression of the disease and improve quality of life, improving memory, and having a beneficial effect on behaviour and activities of daily living. This evidence is supported by the testimonies of great numbers of people with dementia and their carers.

These medicines are called Cholinesterase inhibitors and include Donepezil (Aricept), Rivastigmine (Exelon) and Galantamine (Reminyl). They have been shown to be effective in approximately two thirds of people with Alzheimer's and Lewy Body Dementia, in the mild to moderate stages of the disease, delaying deterioration and enabling people to stay independent longer.

In addition, another medicine called Memantine (Ebixa) may be used in the moderate to severe stages of dementia, either as well as cholinesterase inhibitors or on its own, primarily to assist with behavioural symptoms. (Memantine is known as an NMDA receptor antagonist).

People with dementia can also have depression. Antidepressants are often used to lift mood, calm anxiety and assist with sleep. Despite some claims to the contrary, there is no evidence that cardioprotective medication such as aspirin, ACE inhibitors and statins slow the progression of dementia. It is widely agreed, however, that it is sensible to optimise cardiovascular risk factors.

Some drugs are known to have side effects including sedation, shakiness and unsteadiness and to lead to an increased risk of falls. This makes the need for careful monitoring critical.

Case for Change

Not everyone is assessed and diagnosed in a timely way and this can result in people being excluded from any drug treatments that may have benefits.

Best Practice

Everyone who is diagnosed with dementia through memory assessment services in Birmingham and Solihull is assessed as to their potential suitability for dementia medication.

Birmingham Community Healthcare Learning Disabilities service prescribes dementia medications and long term follow up as per NICE guidelines. Medication rationalisation and concordance is part of a clear review process through individual treatment plans.

Define the Changed State

I will be given a trial of anticholinesterase medication (where appropriate) following my diagnosis with dementia.

I have access to 'non-drug' treatments when I exhibit behavioural and psychological symptoms of dementia.

Key actions

1. Ensure everyone who is appropriate is offered 'anti-dementia' drugs.
2. Practitioners to have increased awareness of how to recognise and manage pain relief.

LIVING WELL WITH DEMENTIA

8. Support for families and carers including respite services and day services

> *"Perhaps I don't, sort of, say often enough how much I appreciate what my wife is doing. I've had more help than hindrance and, as far as she is concerned, I mean, bless her cotton socks, I mean, she deserves an Oscar. She is the one who needs congratulations and whatever, she's been amazing."*
>
> **One man expressing his gratitude towards his wife**

Background

An estimated 670,000 people in the UK act as primary carers for people with dementia, saving the state approximately £8 billion. Trends towards more dispersed families and more women working mean there will be fewer family carers to look after people with dementia.

We know that the contribution of informal carers makes substantial savings to the public purse. We also know that many carers feel isolated and excluded. The nature of caring and the reality, for them, of stigma means that their lives are significantly affected in a number of ways by their caring responsibilities, with little attention paid to the impact on them.

The term carer is more formally applied to people who look after a friend, relative or neighbour who has a long-term disability, mental health difficulty, or is frail due to old age, and the person is not paid for the care they provide. They may be helping them with:

- Personal care, such as washing, dressing or taking medication
- Practical care, such as support with shopping, cooking and cleaning
- Emotional support if they are lonely, worried or get upset.

Talking to carers we know that their needs include:

- Social activities/support
- Advice and education
- Respite/crisis support
- Domestic support
- Nursing support
- Financial support

Social – Access to an increased range of 'active therapies' provides social interaction for carers. Currently in Birmingham and Solihull there are Memory and Dementia Cafés, Singing for the Brain and Dementia Information and Support for Carers (DISC).

The Growing Older with Learning Disabilities and Dementia in Birmingham (GOLDD) service provides day care for people with learning disabilities and dementia.

Advice and education – There is some evidence that structured carer education can be effective at reducing the need for institutionalised care. Dementia support and advice services and carer support services such as DISC provide information to carers to help support them in their carer role and training.

Respite/crisis support – Day respite can be provided for short periods in a range of different ways, either in the home or in day centres for older people through Age Concern for Birmingham.

Crossroads – Caring for Carers service in Solihull provides respite support in the home.

Nursing support – The Admiral Nursing service offers specialist dementia nursing support to family carers with multiple and complex care needs, both emotionally and practically, using a range of therapeutically evidenced interventions. This service is provided in partnership between Birmingham and Solihull Mental Health Foundation Trust with Dementia UK.

It works with carers in identifying areas of difficulty they are having in their carer role, and helping them to manage this effectively. The interventions provided include, psychological interventions, short-term solution-focused therapy, behavioural family therapy, or longer-term bereavement/loss counselling.

Financial support – The main financial benefits for carers are Carers Allowance (a state benefit that some carers can claim) and Carers Break Grants of £250 which some local authorities will provide.

Carers assessment – On request, both Birmingham and Solihull local authorities will provide a free assessment of anyone who is providing substantial and regular care for someone.

Case for Change

While some services exist to support carers they are not universally accessible, and there is often poor communication and co-ordination between services. Carers need easy-to-access co-ordinated services that will consistently meet their needs.

Carers of people from minority ethnic groups with dementia may feel reluctant to ask for help, although support in the form of carers' groups and respite services may be appreciated.

Residential respite is available across the area but many people feel it is very difficult to find.

Best Practice

Dementia Information and Support for Carers (DISC) service, jointly funded by Birmingham City Council and the NHS, is specifically to support carers of people with memory problems at all stages of their journey.

The Alzheimer's Society provides an online forum Talking Point, which enables carers to seek support on a wide range of issues.

Solihull has a range of services available to carers, including carer support workers, a carers' support scheme (provided through Age UK), and Caring for Carers (provided through Crossroads), as well as a carers' support group in south Solihull.

Define the Changed State

As a carer I will feel less isolated and more able to access the support and help I need. This will reduce stress and carer isolation, which will help prevent crises for both me and person with dementia.

As a carer I will be able to get a break from caring while the person I care for is enjoying themselves or I can join in and get mutual support from other carers.

Families and carers will feel better supported to understand and cope with caring.

My carer will have his/her own care plan and information about where to get help quickly when he/she is struggling to cope.

Key Actions

1. Carers' assessments to be offered to all carers.
2. Assist carers to develop informal peer networks.
3. Assist ex-carers to become mentors.
4. Increase availability of respite/short breaks.

INCREASING CARE

1. Good care in general hospitals

> *"If the person I care for is admitted to hospital I will be involved in their care planning and secure in the knowledge that they will be treated with dignity and respect in a suitable ward environment."*
>
> **National Dementia Declaration – A Call to Action**

> *"I know that my mother going into hospital means I am going in as well – no-one there will look after her – I cannot leave her in there on her own."*
>
> **Carer talking about her experiences**

Background

Some of the most passionate feedback we got through our discussions with carers was around care in acute hospitals, with carers describing poor physical care that left them unwilling to leave their loved ones alone in the hospital.

National evidence suggests that, at any one time, a quarter of hospital beds are taken by people over the age of 65 with dementia[35], and 97 per cent of nursing staff report that they always or sometimes care for a person with dementia. Across Birmingham and Solihull there has been a steady increase in the number of emergency admissions to acute hospitals of patients with a primary or secondary diagnosis of dementia.

To see our video visit **www.vimeo.com/61705797**. To access the paper copy of 'Connected Compassionate Communities' **Click here**

There is evidence that suggests that people with dementia:

» Are hospitalised for longer periods than those admitted for similar medical conditions without dementia[36]
» Often experience a deterioration in their physical health and an increase in dementia symptoms while they are in hospital
» Have fewer options on discharge, or are more likely to be discharged to a care home, even if they were previously living in their own home
» Have poorer outcomes compared with someone who has the same clinical condition but who does not have dementia
» Will be supported by staff who do not have the right training, skills and expertise to manage their needs appropriately.

Our work echoed the findings of other studies, and highlighted:

» Nurses not recognising or understanding dementia
» Lack of personal care
» Patients not being helped to eat and drink
» Lack of opportunity for social interaction
» Patients/carers not having as much involvement in decision making as they would like
» The person with dementia not being treated with dignity.

The increased risk of falls that accompanies dementia and the existence of other serious physical health conditions in the elderly, means hospital admission can often be a fact of life.

Case for Change

Wards and other hospital services should be easy and comfortable for people with dementia to find their way around. This may mean simple improvements in social areas, better signage and easy-to-read information.

Staff should be able to ensure patients eat and drink enough and should be trained in how to communicate with people who have dementia.

There should be a focus on preserving independence, and enabling discharge back home.

Best Practice

Acute hospitals across Birmingham have developed initiatives aimed at improving the quality of care for people with dementia. These include offering activities that encourage mobility, clinical services that focus on managing care, adaptations to environment including to layout and signage, staff training and dementia champions.

Define the Changed State

I will only be admitted to hospital where no other safer alternative exists and I will only stay there for as long as I need that level of care.

I will be treated in dementia-friendly wards.

I will only be given antipsychotic and other tranquilliser medications where there are no safer alternatives.

I will be offered out-of-hospital services if needed to ensure that I am able to return home wherever possible.

My carer will be welcomed as an essential partner in care.

Key Actions

1. Hospitals will ensure all wards and services are dementia friendly.
2. Workforce will have appropriate knowledge and skills around dementia.
3. People with dementia offered 'All About Me' document.
4. There will be effective mental health liaison services in place.
5. People with dementia to have access to intermediate care services on discharge from hospital.
6. Reduce unnecessary delays in discharge from hospital.

> “National evidence suggests that, at any one time, a quarter of hospital beds are taken by people over the age of 65 with dementia, and 97 per cent of nursing staff report that they always or sometimes care for a person with dementia.”

INCREASING CARE

2. Living well with support and care

> *"I will have access to services that support me to stay as independent as possible."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"Help …. happens very slowly. It took about four months for someone to come and see me and then it took a further three months …. So it does take a long time and I think a lot of carers would say that the sufferer has changed while you are actually waiting."*
>
> **Quote from carer – Transitions**

Background

While people can live well with dementia in their own home and community their needs will change over time. This means that services need to be responsive to these changes, wherever the person may live.

As needs increase it becomes more important for all services and agencies to work together with care plans agreed with the person with dementia and their family. Where it is unsafe for people to remain at home residential care may be required.

Health and social care services will seek to bring direct payments and personal health budgets together so that people eligible for both will have the greatest degree of freedom in how they can use this money.

Case for Change

There is the need for better integrated care and support for people with dementia and their carers/family, to enhance the quality of life for all those affected by dementia, and for mental health expertise to support care providers working with people with dementia.

Best Practice

Solihull Enhanced Assessment Service provides specialist in reach support to the Virtual Ward team. This ensures that people with complex physical health needs as well as dementia can continue to have their needs met at home rather than be admitted to hospital.

Define the Changed State

I know that I can ask for a social work assessment for myself and the person who is caring for me and that these assessments will be reviewed regularly for both of us.

I have information about what services are available and the support that they can provide.

I know that I can ask for a direct payment that would give me more control over the services that we receive.

I know who to contact when we are struggling to cope or our needs are increasing.

I know that services are working together and they are keeping me and my family well informed.

Key Actions

1. Workforce in social care and health appropriately trained.
2. Access to personal budgets and continuing healthcare for those who qualify.

INCREASING CARE

3. Managing changes in behaviour

> *"If my mood or behaviour changes I know that those who care for me will be able to access services that provide additional support to me and my carer."*
>
> **National Dementia Declaration – A Call to Action**
>
> *"He used to be an engineer and he was very precise in everything he did, and now when he gets problems doing things he gets very frustrated. Very frustrated. He gets angry and he'll shout at me, 'I never used to be like this'."*
>
> **National Dementia Strategy**

Background

Between 60 and 90 per cent of people with dementia may exhibit a range of behaviours that may challenge during the course of their illness.

These difficulties are collectively referred to as the Behavioural and Psychological Symptoms of Dementia (BPSD). BPSD can be distressing for the person with dementia, their family and carers, and may make it difficult to provide or receive care.
They can be the result of agitation or the person's frustration with their cognitive state, however, they can also occur for many other reasons including the organic changes occurring in the brain.

Behaviours may also become evident in relation to uncomfortable environments (including if people are experiencing physical pain), hallucinations, depression or the need for social contact and stimulation. BPSD are usually transient for either a few hours, days or weeks and can mostly be managed with supportive psychological therapies, including some simple calming and relaxation techniques.

The prescribing of antipsychotic drugs is the most common medical intervention in BPSD, however, clinical evidence reveals limited effectiveness of antipsychotic use in dementia and highlights patient safety concerns due to the increased risk of stroke, other cerebrovascular problems and death among older people.

Case for Change

In 'The right prescription: a call to action on the use of antipsychotic drugs for people with dementia', the Alzheimer's Society responded to the issues of patient safety alongside other concerns[36]. Now the emphasis is to ensure the use of antipsychotic drugs to manage BPSD are part of a managed treatment regime and a target is to reduce prescribing levels.

Best Practice

The Older Adults Learning Disability Psychology team in Birmingham offer input with Behavioural and Psychological symptoms of dementia (BPSD). Birmingham and Solihull Mental Health Foundation Trust has introduced clear best practice clinical guidelines for managing challenging behaviour and psychological symptoms in dementia (BPSD) for staff working with people with dementia.

Define the Changed State

Wherever possible my behaviour will be managed by non-drug options.

If the person I care for starts exhibiting difficult behaviour I will be supported to manage this behaviour without resorting to medication in the first instance.

If I have challenging behaviour my GP and other health professionals will know how to get support to manage it without medication and will know how to assess if there is anything other than dementia that is causing my behaviour and how to treat/manage that.

Key Actions

Audit usage of antipsychotic medication.

INCREASING CARE

4. Specialist mental health care

> *"Admission to an inpatient unit should have a clear objective that is shared from the outset with the person with dementia, the carer, and the multidisciplinary team. When the objective has been achieved, there should be an efficient discharge process, supported by community resources."*
>
> **NICE Clinical Guideline**

Background

We know from people with dementia that support from specialist mental health services in the community can be invaluable. It ensures that they can continue to live independently, can help to avoid 'crisis' admissions to both mental health inpatient services and acute general hospitals, and can help them to adapt to home life following discharge from an inpatient episode. Additionally, for other professionals in primary care, in acute hospitals and care homes can help with the recognition and management of people with dementia and in dealing with a crisis.

Birmingham and Solihull Mental Health Foundation Trust provides a range of specialist mental health services for older adults, including acute inpatient services for those with severe and complex needs who cannot be supported for safe assessment and treatment in the community. This will include people who have been detained compulsorily under mental health legislation. These specialist services are centres of expertise in dementia care. They also provide a range of specialist services in community settings including the memory assessment service in Birmingham and Solihull, community mental health teams, Specialist Therapy and Engagement Programme (STEPS) and Community Enablement and Recovery Team (CERT).

People presenting with the most complex needs are likely to have a higher incidence of physical health and care needs. Specialist community mental health services for dementia are focused on the assessment and diagnostic process and early interventions, as well as those people with the most complex needs. People with dementia should be admitted to specialist inpatient care only when it is the most appropriate option, and admission should be for as short a duration as possible.

Case for Change

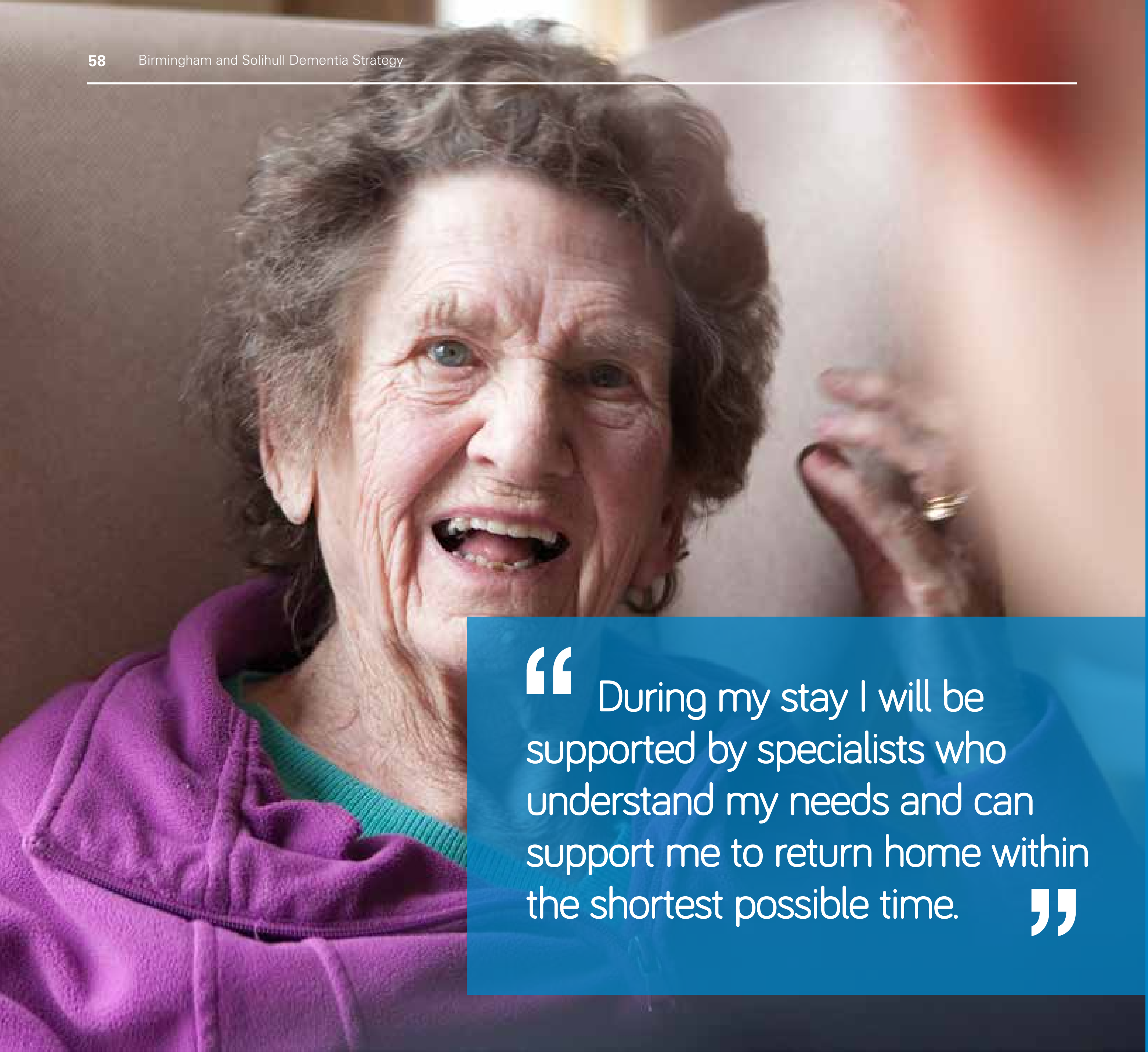
There is limited access to specialist respite/place of safety, both in formal and informal settings.

Best Practice

The Specialist Therapy and Engagement Programme (STEPS) provides community-based assessment and mental health therapies for older people.

The Community Enablement and Recovery Team (CERT) provides discharge and community services that include treatment and support to service users and their carers within the local community. This avoids admission to hospital, or premature entry into residential or nursing home settings, and supports earlier discharge from in-patient units.

A joint policy has been implemented between Birmingham and Solihull Mental Health Foundation Trust and the Learning Disability Service within Birmingham Community Healthcare to ensure that people with a learning disability have access to services that meet both their mental health needs (including dementia) and any needs associated with their learning disability.



> “During my stay I will be supported by specialists who understand my needs and can support me to return home within the shortest possible time.”

Define the Changed State

I will only be admitted to mental health inpatient care if it is the most appropriate option.

During my stay I will be supported by specialists who understand my needs and can support me to return home within the shortest possible time.

I will get access to support from social care while on an inpatient unit so that my carer/family and I will get the right social care support once I return home.

I will be able to access specialist mental health services at the times I need them.

Key Actions

1. Access to advice to families/carers on managing behavioural and psychological symptoms of dementia.
2. Specialist inpatient beds available for assessment and treatment to meet demand.
3. Specialist advice available to GPs, care homes and professionals.

> “People presenting with the most complex needs are likely to have a higher incidence of physical health and care needs.”

INCREASING CARE

5. Living well with dementia in care homes

> *"Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day."*
>
> **NICE Clinical Guideline**

Background

The need to improve the current quality of dementia care within care homes was identified as a priority and reiterated in 'The Prime Minister's Challenge on Dementia' in 2012[37].

About one third of people with dementia live in care homes and about two thirds of people living in care homes have dementia. Supporting someone with dementia to live in their own home can become very difficult. When a family carer can't get a good night's sleep, or is having to manage continence difficulties, or unsafe and unpredictable behaviour, a move to a care home is often the outcome. Similarly, for a person with dementia living alone, a care home may provide the only option.

There are potentially 6,638 beds in residential and nursing homes available across Birmingham as well as capacity commissioned in surrounding areas. These are in around 357 care homes through 189 providers. Of these, 136 homes specialise in older adults, around 60 per cent of total capacity, with 62 of these in dementia.

Local funding has been approved for a pilot project aimed at ensuring nursing and residential homes have cover from nominated GPs. It will also increase support to care homes in terms of weekly ward rounds, training, and help with complex patients and medication reviews.

While people told us that they wanted the choice of staying in their own home for as long as possible, there is some capacity in terms of sheltered and extra care housing, which provides supported living in community settings.

Specialist care home facilities are available for people with learning disabilities and dementia.

Case for Change

The quality of current care home support for people with dementia is variable and some care homes are not doing enough to appropriately care and support people with dementia.

Best Practice

The Care Fit for VIPs framework[38] was developed by the Association of Dementia Studies, led by Professor Dawn Brooker at the University of Worcester. It provides the resources care homes will need to develop person-centered care, helping them to decide how well they are delivering care at the moment and to identify priorities for development. It also provides the information and resources they need to plan and monitor improvements.

Define the Changed State

If I have dementia and live in a care home I will be supported to enhance my quality of life and enabled to feel valued.

Through tools such as 'About me', I will be able to communicate my likes and dislikes so that staff are less likely to resort to what they think I want and are able to support me according to my wishes.

I know that if my behaviour becomes more difficult to manage staff will try to understand the reasons why and use non-drug interventions wherever possible.

I will have the option of dying in my care home setting if I choose.

> “The need to improve the current quality of dementia care within care homes was identified as a priority and reiterated in ‘The Prime Minister’s Challenge on Dementia’ in 2012.”

Key Actions

1. Complete roll out of care homes pilot and development of clear governance in regard to clinical provision.
2. Develop appropriate learning programme for care home staff so that they are able to recognise the symptoms of dementia and how to manage it in that environment.
3. Support the use of tools such as ‘This is me’.
4. Good service specifications defining the range and quality of care that should be delivered and a clear quality and monitoring framework in place that supports the delivery of person-centred comprehensive care.
5. To scope the development of specialist units within care homes that can provide a better environment for those with dementia at end-of-life stage.
6. Provision of a range of therapeutic activities.
7. To monitor the performance of care homes in protecting residents from being prescribed antipsychotic medications unless there is a valid clinical need and that this is reviewed regularly.

INCREASING CARE

6. End-of-life care

> *"I will die with dignity in the place of my choosing."*
>
> **National Dementia Declaration – A Call to Action**

Background

The Department of Health's National End-of-Life Care Strategy (2008)[39] recommended that a framework be implemented in all acute hospitals to ensure delivery of appropriate care for people who are in the dying phase of their illness and after death.

In the community, the Gold Standards Framework (GSF) for palliative care was introduced for the care of people nearing the end of their life. The key principles of good end-of-life care are:

- That people are in their 'preferred' place of care
- That symptoms are controlled
- That care is focused on ensuring comfort at end of life
- That there is support for family at bereavement.

A number of particular issues, with regard to people with dementia, were flagged to us.

These highlighted:

- that many people with dementia were not being supported to have early discussions about their wishes and make plans for their end-of-life care
- that many people ended their life in hospital rather than a place of their choosing because of a lack of other end-of-life provision
- many in care homes ended their life in hospital because care homes felt unable to manage their care at end of life, or because their service protocols dictated, or because families saw this as the only option.

Case for Change

Access to services varies across Birmingham and Solihull.

Best Practice

In Solihull all GPs use the Gold Standards Framework and more than 81 per cent of people die in their preferred place.

Hospice providers have developed specialist end-of-life training for people working with people with dementia and have extended community end-of-life and palliative care services to include dementia.

Define the Changed State

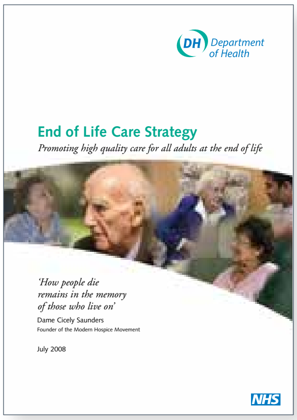
If I have dementia I will be assisted to complete a care plan including end-of-life plans.

I will be able to access end-of-life services in a consistent way across the area.

I will be supported by carers and professionals to help the person I care for to die peacefully in their preferred place.

Key Actions

1. Agree care planning that includes end-of-life care planning for all people with dementia.
2. Providers will have the skills to work with people in the development of future and end-of-life plans.
3. Provide improved access for people with dementia to palliative care services.
4. Improve the treatment and management of pain for the person with dementia.
5. Increase availability of counselling services to support the carer in preparing for and dealing with the death of their loved one.



DH Department of Health

End of Life Care Strategy

Promoting high quality care for all adults at the end of life

'How people die remains in the memory of those who live on'

Dame Cicely Saunders

Founder of the Modern Hospice Movement

July 2008

NHS

NEXT STEPS

The dementia strategy has set out the reasons why we need to adapt and improve the support available for people with dementia and their family/carers, and offers a list of key actions that will help commissioners, provider organisations and all those with an interest in dementia, to plan for the future.

The predicted rise in the number of older people in the next two decades will see a rise in the number who are diagnosed with dementia. As investment in public services continues to stagnate or even fall, it is necessary for us to get more value out of every pound spent, and for all of us as citizens to play our part in living healthy lifestyles and helping our family in times of need.

Using this table as a template we now invite our partner organisations to:

- Sign up to this strategy
- Make plans to achieve those actions that relate to their organisation
- Ensure their staff have the skills and support to achieve service improvements.

We have identified a number of themes that are key to the strategy becoming operational. They include:

1. Developing communities to be dementia friendly to support them to reduce stigma and promote equality
2. Promote an ageing well agenda, building on the resources available within communities to support people with dementia and their carers to live a more normal life
3. To diagnose dementia earlier
4. To improve the quality and reduce the variation of care available to people with dementia and their carers. This will involve a more integrated approach from providers, giving greater access to more comprehensive support that enables people to live independently
5. We need to recognise the transformational shift that will be required in the way we provide care and support that will require all staff and carers to have the correct skills and information in order to provide high-quality care with dignity, respect and compassion.

As commissioners, we intend to review the strategy annually so that we can see what progress is being made. This allows the public to hold us and service providers to account. We also want people with dementia and their family/carers to be part of the review and to have a say in how services and investment are planned. We therefore propose to establish a Dementia Partnership Forum that will:

- Have representation from people with dementia, their family/carers, commissioners, professionals and provider organisations
- Be a forum to share information on good practice and to comment on services in Solihull and Birmingham
- Lead the annual review of the dementia strategy and report on progress to commissioners and providers.

Commissioners will want to be satisfied that all of the actions undertaken:

- Promote independence and activity, enhance life quality, and delay the need for care away from home
- Allow people to make informed choices, have a positive experience of care, and have control of their care
- Make use of the strengths and resources of local communities
- Recognise and respect the diversity of people and communities
- Keep people safe.

Key Action	Outcomes / Measures	Key People	Local response and timelines (for reviews)
1. Health Promotion and Prevention			
1.1 Raising Awareness and Understanding			
Local Publicity Campaign	Increased awareness of healthy lifestyles, dementia, and support services	» Health & Wellbeing boards » CCG and local authority commissioners	
Include dementia in local strategic planning	Better commissioning of dementia services	» Health & Wellbeing boards » Commissioners for CCGs and local authorities	
Sign up to Dementia Action Alliance principles	Key Stakeholders commit to better understanding of dementia	» Chief Executives of commissioning and provider organisations	
Include early identification of dementia as a priority for health and social care services	Increase in numbers offered assessment	» GPs » CCGs » Public Health	
1.2 Wellbeing, Health Promotion, Prevention, Delaying Onset			
Promotion of principles of primary care direct enhanced service	Improved support for people with dementia and carers in primary care	» GPs » CCGs » Public Health	
The frail elderly, including those with early stages of dementia, will have access to services that promote health and well being and reduce social isolation	Improved health Reduction in crisis admissions to acute hospitals and residential care	» Public Health » CCGs » GPs	
Staff in long term condition clinics will be trained to identify potential symptoms of early stage dementia	Improved recognition of dementia	» CCGs » Specialist Commissioners	
Linking of "what is good for the heart is good for the brain" promotion	Improved health	» Public Health	
1.3 Dementia Friendly Communities			
Promote community development programmes and small grant programmes	Increased community understanding of dementia	» Commissioners for CCGs and local authorities	
Publicise dementia friendly communities	Increased community understanding of dementia	» Commissioners for CCGs and local authorities	

Key Action	Outcomes / Measures	Key People	Local response and timelines (for reviews)
2. Recognition and Identification			
2.1 Case for Early Detection			
Agree a consistent recognition and referral pathway for primary care	Improved recognition of dementia	» GPs » Memory Assessment Service	
Set targets for increasing diagnosis rates	Improved diagnosis rates	» CCG commissioners » GPs » Memory Assessment Service	
2.2 Casefinding			
Agree recognition tool for use by health and social care professionals	Improved recognition of dementia	» GPs » Psychiatrists » Memory Assessment Service » Commissioners	
Ensure access to learning and support to professionals, including those working with learning disabilities, substance misuse and people in custody	Increased recognition of dementia Increase in rates of diagnosis	» Workforce development teams	
2.3 Recognition and referral including acute hospitals			
GPs and health and social care professionals to be proactive in identifying high risk groups	Increased recognition of dementia Increase in rates of diagnosis	» GPs » Health and social care professionals » Birmingham Community Healthcare NHS Trust	
Hospitals to carry out cognitive screening of non-elective admissions and people with long term conditions	Increased recognition of dementia Increase in rates of diagnosis	» Acute providers and commissioners » Birmingham Community Healthcare NHS Trust	
Hospitals have access to expert advice on dementia	Increased recognition of dementia Increase in rates of diagnosis Better outcomes for people with dementia in acute settings	» Acute providers and commissioners	
2.4 Mild Cognitive Impairment (MCI) and Subjective Cognitive Impairment (SCI)			
Agree a common approach to MCI and SCI, including recognition and support in primary care	Increased wellbeing of 'at risk' groups	» GPs » Memory Assessment Service	

Key Action	Outcomes / Measures	Key People	Local response and timelines (for reviews)
3. Assessment, Diagnosis and Planning for the Future			
3.1 Assessment and Diagnosis			
Agree clinical pathways	Increased referral rate for assessment	» GPs » Memory Assessment Service	
Agree governance for memory assessment	Improved patient experience	» GPs » Memory Assessment Service	
External monitoring of memory assessment service	Ensure service is in line with national quality guidelines	» MSNAP for BMAAS	
Training for GPs around learning disabilities and recognition of dementia			
3.2 Early Support and Treatment			
All people diagnosed with dementia are offered a dementia adviser	People with new diagnosis have appropriate information and support	» Memory Assessment Service » Alzheimer's Society » Commissioners	
People newly diagnosed are offered treatment where clinically appropriate	Improved quality of life for people with dementia	» MAS » Alzheimer's Society » Commissioners	
4. Living Well With Dementia			
4.1 Living well			
Assist people with dementia and their families/carers to access support to maintain quality of life	More people to be independent for longer	» Primary care » Social care » Leisure services » Third sector	
Engage people with dementia and their families/carers in commissioning decisions	Better planning and commissioning	» Commissioners	
4.2 Planning for the future			
All people with dementia to have access to dementia support	Support in place and assistance with navigation to care services	» Commissioners » Alzheimer's Society » Memory Assessment Service	
People with dementia to be able to create a life diary	Improved quality of life and better management of condition for people with dementia	» Commissioners » Alzheimer's Society » Memory Assessment Service	

Key Action	Outcomes / Measures	Key People	Local response and timelines (for reviews)
Services cater for wide range of options, including meeting needs of ethnically diverse population	Improved rates of diagnosis Equitable access to services	» Commissioners » Service providers » CCGs	
4.3 Support along the journey			
Re-launch clinical and community support pathways	Improved rates of diagnosis	» GPs » Commissioners	
Advice and information available to carers	Improved rates of diagnosis Reduction in crisis admissions to acute hospitals and residential care	» Commissioners » CCGs » Alzheimer's Society	
4.4 Staying safe and secure at home			
Joined up assessments between health and social care	Holistic care and support for people with dementia	» CCGs » Local authorities	
Access to re-ablement and telecare services	People with dementia can retain daily living skills	» Local authorities » Commissioners	
Workforce development programmes	Improved awareness of dementia by health and social care staff	» CCGs » Local authorities	
Commissioning process to support community assets	Procurement of third sector services and support to community groups	» Commissioners for CCGs » Local authorities	
4.5 The right medication			
Audit use of antipsychotic medication	Reduction in use of antipsychotic medication as per NICE guidance	» GPs » Psychiatrists » Commissioners	
Practitioners to have increased awareness of how to manage pain relief	Improved quality of life for people with dementia	» Commissioners » Service providers	
4.6 Support for families and carers			
Carers' assessment offered to all	Reduced crisis admissions to acute and residential care	» Local authorities » Other service providers signpost	
Advice available to all carers	Development of website	» Commissioners » Local authorities	
Assist carers to develop informal peer networks	Reduced crisis admissions to acute and residential care	» Alzheimer's Society	
Assist ex-carers to become mentors	Reduced crisis admissions to acute and residential care	» Alzheimer's Society » Commissioners	
Increase availability of respite/short breaks	Reduced crisis admissions to acute and residential care	» Local authorities	

Key Action	**Outcomes / Measures**	**Key People**	**Local response and timelines (for reviews)**
5. Increasing Care			
5.1 Good care in general hospitals			
Hospitals to ensure wards are dementia friendly	Improved outcomes for people with dementia Reduced delayed transfers of care	» Hospital Trusts » Birmingham Community Healthcare NHS Trust	
Workforce with appropriate knowledge and skills	Improved outcomes for people with dementia Reduced delayed transfers of care	» Hospital Trusts » Birmingham Community Healthcare NHS Trust	
People with dementia offered "This About Me" document	Improved outcomes for people with dementia Reduced delayed transfers of care	» Hospital Trusts » Birmingham Community Healthcare NHS Trust	
Effective liaison services in place	Improved outcomes for people with dementia Reduced delayed transfers of care	» Hospital Trusts » Mental Health Trust » CCG commissioners » Birmingham Community Healthcare NHS Trust	
People with dementia have access to Intermediate Care	Increased potential for return to home setting	» CCG commissioners Community Trusts » Hospital Trusts	
Reduce unnecessary delays in discharge	Increased potential for return to home setting	» Hospital Trusts » Local authorities » Birmingham Community Healthcare NHS Trust	
5.2 Living well with support and care			
Workforce in social care and health appropriately trained	Improved access to signposting and referral for people with dementia	» Local authorities » Home support providers » Commissioners	
Access to personal budgets and continuing healthcare for those who qualify	Choice in services	» Local authorities » Commissioners	
Access extra care sheltered housing	Maintain independence longer	» Local authority housing service	
5.3 Specialist mental health care			
Advice to families/carers on managing behavioural and psychological symptoms	Reduced crisis admissions to acute and residential care	» Mental Health Trust » Commissioners	
Specialist inpatient beds available for assessment and treatment	Reduced crisis admissions to acute and residential care People with dementia able to access appropriate care	» Commissioners » Mental Health Trust	

Key Action	**Outcomes / Measures**	**Key People**	**Local response and timelines (for reviews)**
Specialist advice available to GPs	Improve rate of diagnosis Supported management of long term conditions in primary care	» Mental Health Trust » Commissioners	
5.4 Living well with dementia in care homes			
Complete roll-out of care home locally enhanced service	Better access for care homes to primary care support	» GPs » CCGs	
Workforce have appropriate knowledge, tools and skills	Reduce crisis admissions to acute and residential care Reduced use of anti-psychotic medications for people with dementia	» Care homes » Acutes » CCGs » Mental Health Trust » Birmingham Community Healthcare NHS Trust » Commissioners	
Each care home has a dementia champion	Reduced crisis admissions to acute and residential care Reduced use of anti-psychotic medications for people with dementia	» Care home managers » Commissioners	
Specialist in-reach to reduce the need for hospital admission	Reduced crisis admissions to acute and residential care Reduced use of anti-psychotic medications for people with dementia	» Mental Health Trust » Commissioners » CCGs » Acute Trusts	
Scope development of specialist units within care homes for those at end of life	People with dementia able to die in place of choosing	» Commissioners » Care home managers	
Care homes provide range of social and therapeutic activities	Improved quality of life for people with dementia	» Commissioners » Care home managers	
5.5 End of life care			
Workforce have knowledge and skills to provide end of life care	People with dementia able to die in place of choosing	» Commissioners » Service providers	
Improved access for people with dementia to palliative care	People with dementia able to die in place of choosing	» Commissioners » Service providers	
Improve treatment and management of pain for people with dementia	People with dementia able to die in place of choosing	» Commissioners » Service providers	
Increase availability of counselling for bereaved carers	Better End of Life care	» Commissioners » Service providers	

APPENDIX ONE

Useful Documents

National

Living well with Dementia – A National Dementia Strategy (2009)
www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (2011)
www.gov.uk/government/publications/quality-outcomes-for-people-with-dementia-building-on-the-work-of-the-national-dementia-strategy

The Prime Minister's Challenge on Dementia – Delivering major improvements in dementia care and research by 2015
www.gov.uk/government/news/prime-minister-s-challenge-on-dementia

Delivering major improvements in dementia care and research by 2015: Annual Report of progress
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200030/9535-TSO-2900951-PM_Challenge_Dementia_ACCESSIBLE.PDF

Dementia UK 2007
www.lse.ac.uk/newsAndMedia/news/archives/2007/AlzheimersReport.aspx

Dementia 2010 The Economic Burden of Dementia and associated research funding in the United Kingdom. The Alzheimers Research Trust
http://www.dementiapartnerships.org.uk/archive/resource/dementia-2010-research-funding/

The Operating Framework for the NHS in England 2012/13
www.gov.uk/government/publications/the-operating-framework-for-the-nhs-in-england-2012-13

Equity and Excellence – Liberating the NHS (white paper)
www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf

No Health without Mental Health Department of Health 2011
www.gov.uk/government/publications/the-mental-health-strategy-for-england

National Dementia Declaration for England – A Call to Action
www.dementiaaction.org.uk/assets/0000/1157/National_Dementia_Declaration_for_England.pdf

Pan West Midlands adult safeguarding P&P
www.scie.org.uk/publications/reports/report60/introduction.asp

Statement of government policy on adult safeguarding
www.gov.uk/government/publications/adult-safeguarding-statement-of-government-policy-10-may-2013

NHS accountability framework
www.england.nhs.uk/wp-content/uploads/2013/03/safeguarding-vulnerable-people.pdf

Counting the cost: caring for people with dementia on hospital wards. Alzheimer's Society (2009)
www.alzheimers.org.uk/countingthecost

Paying the Price: the cost of Mental Health care in England to 2026 (May 2008)
Paul McCrone, Sujith Dhanasari, Anita Patel, Martin Knapp, Simon Lawton-Smith
www.kingsfund.org.uk/publications/paying-price

NICE Clinical Guideline 42 – Supporting people with dementia and their carers in Health and Social Care (2006)
http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf

Dementia Commissioning Pack (DH 2011)
www.gov.uk/government/publications/dementia-commissioning-pack

Using the Commissioning for Quality and Innovation payment framework – Guidance on new national goals for 2012-13 (DH 2012)
www.gov.uk/government/uploads/system/uploads/attachment_data/file/215049/dh_133859.pdf

The use of antipsychotic medication for people with dementia: Time for action. A report for the Minister of State for Care Services by Professor Sube Banerjee. Department of Health 2009 (PDF)
www.psychrights.org/research/digest/nlps/BanerjeeReportOnGeriatricNeurolepticUse.pdf

'Dementia and People with Learning Disabilities'
British Psychological Society (BPS) and the Royal College of Psychiatrists (RCP)
www.downs-syndrome.org.uk

Local

Birmingham Joint Strategic Needs Assessment – Mental Health 2011

APPENDIX TWO

Useful Sites

Birmingham and Solihull Mental Heath Foundation Trust	*www.bsmhft.nhs.uk*
Alzheimer's Society	*www.alzheimers.org.uk*
Alzheimer's Research UK	*www.alzheimersresearchuk.org*
Dementia Information and Support for Carers (DISC)	*www.discbirmingham.co.uk*
Age UK	*www.ageuk.org.uk*
Birmingham City Council	*www.birmingham.gov.uk*
Birmingham City Council Adult Social Care	*www.mycareinbirmingham.org.uk*
Solihull Metropolitan Borough Council	*www.solihull.gov.uk*
Carers Emergency Response Service (Birmingham)	*www.cers.org.uk*
The Dementia Action Alliance	*www.dementiaaction.org.uk*
Admiral Nurses	*www.dementiauk.org/what-we-do/admiral-nurses*
Dementia UK	*www.dementiauk.org*
NHS Choices	*www.nhs.uk*
The Care Quality Commission	*www.cqc.org.uk/public*
Dementia Prevalence Calculator	*www.dementiaprevalencecalculator.org.uk* *whealthpartnerships.com* *www.dementiapartnerships.com*
Mental Health Partnerships	*www.mentalhealthpartnerships.com*
Dementia Partnerships	*www.dementiapartnerships.com*

Connected Compassionate Communities videos

By Naidoo & Associates	More information available at *mail@naidoo.org*
1. Introduction narrative of people living with dementia, their carers and family members – issues and perceptions	*www.vimeo.com/61190089*
2. Recognition, Assessment and Diagnosis	*www.vimeo.com/61050579*
3. Living with dementia	*www.vimeo.com/61029795*
4. Residential, secondary, end of life care	*www.vimeo.com/61705797*
5. End piece – celebration of life affirming energy	*www.vimeo.com/58200081*
6. Summary of videos 1-5 with selected narrative	*www.vimeo.com/63396880*

APPENDIX THREE

List of Contributors

Dr Patrick Brooke	Chief Officer	NHS Solihull CCG
John Short	Chief Executive	Birmingham & Solihull Mental Health Trust
Mary Latter	Joint Commissioning Manager	Birmingham & Solihull
Michael Kay	Senior Strategic Commissioning Manager	Birmingham
Julia Phillips	Senior Strategic Commissioning Manager	Solihull
Rosina Hall	Service Development Manager	Birmingham & Solihull Mental Health Trust
Bernie Blackledge	Support Services Manager	Alzheimer's Society
Margaret Harries	Lead Nurse, Older Adults	University Hospital Birmingham
David Ratcliffe	Locality Development Officer	Alzheimer's Society
Gary Crellin	Associate Director	Birmingham Community Healthcare
Sarah Smith	Head of Communications, Marketing and Membership	NAIDOO and Associates
Tapshum Patni	Associate Director Social Work, Social Work Development	Birmingham City Council
Victoria Coker	Lead Practitioner for Older People	Birmingham City Council
Sue Turner	Chief Executive (Retired 2012)	Birmingham & Solihull Mental Health Trust
Brian Toner	(Retired 2013)	Birmingham & Solihull Mental Health Trust

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