



Dementia strategy for Solihull 2017 - 2020

Quality of life is important
- living well with dementia

Prevention and Health Promotion

Recognition and Identification

Assessment and Diagnosis

Living Well with Dementia

Increasing Care
(including End of Life Care)

Introduction

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.

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

Dementia is not a normal part of growing old. We know from what people have told us that it is possible to still live well 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.

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 people who are left so vulnerable with the illness.

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Outcomes from the previous Strategy

- 1) **Raising awareness and understanding** - Completed an awareness campaign via Community Pharmacies in June 2016.
- 2) **Wellbeing health promotion, prevention, delaying onset** - Public Health Teams continue to promote the NHS Health Checks that are available from 40yrs to 74yrs and includes a discussion about dementia particularly as there things people can do to help prevent 'vascular dementia'.
- 3) **Dementia-Friendly Communities** - The Council and BSOL CCG have encouraged and supported the establishment of a Community Interest Company that supports both people living with dementia and their carers. This Company is called ACT on dementia. There are now in excess of 8000 Dementia Friends either living or working in Solihull. There were less than 2000 when we started to promote the Dementia Friends Initiative in 2014. There is now a functioning Solihull Dementia Action Alliance with just under 50 members. There were only a small number of members in 2014 and they were not functioning as a group. The members are organisations and businesses like Touchwood Shopping Centre that are working to reducing the stigma around dementia to make Solihull a 'dementia friendly' place to live.
- 4) **Case for early detection** - GPs have a clear pathway to refer people suspected of having a dementia to the Memory Assessment Service for a diagnosis and to access 'post diagnostic support'. NHS England who have set a national diagnosis target of 67% and BSOL CCG are monitored on this.
- 5) **Case Finding/Making Every Contact Count** - Awareness of the early signs of dementia has been promoted by the local Public Health Team through it 'making every contact count' (MECC) initiative.
- 6) **Assessment and Diagnosis** - External monitoring of Memory Services National Accreditation Programme (MSNAP) is in place. This has been achieved by our local Memory Assessment Service.
- 7) **Early Support** - This is a clear requirement for the Memory Assessment Service to ensure that people that have been diagnosed with dementia are referred to the Dementia Navigation Service. Carers are 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. This is now a requirement for the Council within the Care Act.

- 8) **Living Well (community inclusion, feeling valued, living normally)** - People with dementia and their family/ carers are assisted to access support to maintain quality of life. This is being provided both by the Dementia Navigation Service and the Information and Advice Hubs provided by the BSOL CCG and Council. Commissioners engage with people with dementia and their family/carers in commissioning decisions. The Commissioners seek advice from a group of people living with dementia when considering developments. This Group is supported by the Dementia Navigation Service and meets weekly. They recently produced a letter from the Group to be given to people who are being newly diagnosed with dementia. There is work with local communities to encourage them to be more visibly welcoming to people with dementia. This is being achieved by the Solihull Dementia Action Alliance.
- 9) **Planning for the future** - All people with dementia have access to support to offer help and guidance with navigating care and other services. This is provided by the Dementia Navigation Service. People with dementia are able to create their own life diary and to be involved in on-going care planning, including advanced care planning. The Dementia Navigation Service promote the use of the 'This is me' document which helps people living with dementia when they meet with various people including other care services such as during an admission to hospital.
- 10) **Support along the journey** - Increased access to carer education, whether through formal courses, a dementia adviser or attendance at structured support groups such as dementia cafés. This is provided by the Dementia Navigation Service and the Admiral Nurse Service. The Council have also launched the 'MyLife Portal' that gives people access to the information they need in Solihull. Through support from the Commissioning Officer for Dementia a Church in the centre of Solihull has established a weekly 'Dementia Café'.
- 11) **Good care in general hospitals** - Hospitals will ensure all wards and services are dementia friendly. The Solihull Hospital has developed their own Dementia Strategy to achieve this. They are working to ensure that their workforce will have appropriate knowledge and skills around dementia.
- 12) **Living well with dementia in care homes** - Good service specifications defining the range and quality of care that should be delivered and a clear quality and monitoring framework is in place that supports the delivery of person-centred comprehensive care. These have been developed and are now being used.

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 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.

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 3,273 people in Solihull with dementia. This is predicted to grow by 32 per cent to 4,320 by 2025.

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. 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 that this will grow to £120m for Solihull by 2021.

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.

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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.

Recognition and identification

Getting an early diagnosis relies on professionals being able to recognise and identify symptoms of dementia. In 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.

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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. It is important that their diagnosis helps them to access the support that they need instead of it being used as a reason for exclusion. It is also important 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 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.

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We are working with our partners to improve these quality and access issues.

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.

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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.

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:

- Memory
- Changes in their behaviour and mood
- Communication
- Understanding
- Day-to-day activities such as cooking and personal.

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.

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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. The strategy will be used as an integral part of the planning and decision-making process across 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.

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) 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), 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, which explicitly described the imperative for the Coalition Government in terms of dementia.

Our dementia strategy

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.

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.

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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, the number of people who are 85 and over has increased since 2001. This means that people aged 85-plus now make up 2.7 per cent of the Solihull population – around 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 Solihull we know that the rates of growth differ but we estimate numbers will grow by around 32 per cent, in other words, by around 1000 people in Solihull by 2025.

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 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 Solihull, the 2011 census showed 14.2 per cent of the population classified themselves as part of an ethnic group other than white British (that is around 29,426 people). 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.

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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.

There is still concern about those people who do not receive a diagnosis and nationally this is reflected in a proposed new ambition of increasing the diagnosis rate to at least 67 per cent. This target is one that Solihull will work hard to achieve.

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 costs¹. 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 across the health and social care sector.

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Combining this with the predicted growth in numbers of people with dementia (based on demographic change) of 32 per cent for Solihull by 2025, this would increase the annual costs to around £120m for Solihull.

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.

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 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.

By providing support earlier to people that have a higher risk of dementia we can potentially delay the onset of the disease.

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 as long as possible.

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THE STRATEGY

1. Raising awareness and understanding (Dementia-Friendly Communities)

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'.

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.

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.

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.

Solihull 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.

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The Solihull Dementia Action Alliance now has just under 50 members and has set a target to get up to 75 members by 1st April 2019.

Action

- 1) We will continue to promote the Dementia Friends Initiative to raise awareness amongst the general population in order to reduce the stigma.
- 2) We will continue to support the Solihull Dementia Action Alliance by being an active member. This will involve encouraging the Alliance to grow so that more organisations are actively offering services that enable people with dementia to do the 'every day things' that want to do.

Intended outcomes from the Strategy

People living with dementia will say:

- I am less frightened of dementia.
- I have experienced fewer feelings of stigma because of my dementia.
- I have seen more positive images of people with dementia.
- My community has developed and now has a better understanding of how to support people with dementia and their carers.
- I am able to find my way round my local area and be safe.
- I am able to access the local facilities that I am used to and where I am known (banks, shops, cafés, cinemas and post offices).
- I can maintain my social networks and continue to feel I belong.

2. Wellbeing health promotion, prevention, delaying onset

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 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, 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.

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 and reduce deaths directly attributable to dementia by 30,000 a year.

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

Action

- 1) The Public Health Team will continue to promote and support people to have a healthy lifestyle.
- 2) They will also continue to promote the NHS Health Check Service with GPs.
- 3) GPs will be encouraged to carry out assessments and testing for dementia in those patients identified as 'at risk' who may be showing early signs of dementia.

Intended outcomes from the Strategy

People living with dementia will say:

- I can access advisory services as well as leisure options that will help me maintain good health and raise awareness of risk factors.
- I am aware and feel able to live healthily to reduce my risk of developing dementia and delaying potential cognitive decline.

3. Case for early detection

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 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 under 60 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 Solihull, a referral to Secondary Care for a specialist assessment.

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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.

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.

There is evidence to support the benefits of early diagnosis, intervention and on going 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.

Action

- 1) GPs will be encouraged to promote the benefits of an early diagnosis.
- 2) GPs will continue to be an access point for people to get a formal diagnosis once any reasons for the symptoms have been ruled out.

Intended outcomes from the Strategy

People living with dementia will say:

- I am aware of the early signs of dementia and understand the benefits of early diagnosis.

4. Recognition and Referral including in acute hospital settings

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.

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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.

Action

- 1) GPs and other Practitioners will continue to promote the need identify possible dementia as early as possible both in Primary Care and Hospital settings.
- 2) GPs and other Practitioners will ensure that people who have been diagnosed with dementia are referred onto or sign-posted to post diagnostic support services.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I, and my carer, will already have recognised a problem by the time it reaches specialist assessment.
- 2) 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.
- 3) I will be able to easily find out about local dementia services and dementia-friendly activities.

5. Assessment and Diagnosis

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 Solihull, GPs play 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.

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 initial 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 have been accredited through the Memory Services National Accreditation Programme (MSNAP).

All clinical commissioning groups 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.

Action

- 1) During the Assessment Process people will be kept informed about what is happening.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) 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.

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3) 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.

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

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

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

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

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

Background

In 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. This will follow up if the person with dementia does not feel able to use the service immediately following diagnosis.

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

Services such as the Dementia Advisers and Dementia Support Workers (The Dementia Navigation Service) provide support to people with dementia and their carers following a diagnosis.

Action

- 1) The Memory Assessment Service will continue to offer personalised support plans for people who have been diagnosed with dementia.
- 2) The Dementia Navigation Service will continue to offer on-going post diagnostic support to people living with dementia and their families for as long as they need it.

Intended outcomes from the Strategy

People living with dementia will say:

1) 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.

2) 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.

3) My Carer and I will access the post diagnostic support services from the Dementia Navigation Service and the Memory Assessment Service when we need them.

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

Background

In 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.

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 people 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.

Action

- 1) The Dementia Navigation Service will continue to link people with other services that enable the people to do things in the community and feel less isolated.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I will feel less stigma associated with dementia and an increased sense of inclusion and wellbeing.
- 2) I will be able to easily use more community services.

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Increasing Care (including End of Life Care)

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

8. Planning for the future and personalisation

Background

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.

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 local club 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.

Many providers now use 'This is me' – a tool for people with dementia receiving professional care developed by Alzheimer's Society. This allows the 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.

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Solihull Metropolitan Borough Council fund dementia support workers 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.

Action

- 1) The Dementia Navigation Service will continue to have Dementia Advisers and Dementia Support workers who can be available to assist and support people and their carers at what ever point they are in their journey living with dementia.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I will have an assessment and an on-going 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
- 2) I will be offered support to complete life diaries.
- 3) I will be offered support to write future care plans.
- 4) If I am eligible I will be offered and supported to have a personalised care budget.
- 5) I will be offered services that help me plan for the future and access services in a way that suits me.

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

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. People were also clear that they wanted a person-centred problem-solving approach to the issues they faced.

The Dementia Navigation 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.

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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 without on-going support being available.

There is a need to consider the emotional and spiritual needs of people with dementia and their carers at an early stage in their journey.

Action

- 1) The Dementia Navigation Service will continue to enable access to information and support throughout the dementia journey.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I will be able to access specialist dementia adviser type services regardless of where I have been diagnosed.
- 2) My carer and I will have access to information and support throughout our journey.
- 3) My GP will refer me for assessment, and supply information and support to both my carers and I.
- 4) 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.

10. Staying safe and secure at home – Financial, legal and practical support Telerate/assistive technology/home adaptations/home support – 'care at home' and nursing, re-enablement

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.

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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.

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 – Solihull council provides a 'reablement' service 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 ('care at home' 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.

Social care services can include help at home with personal care activities such as washing, dressing, feeding, toileting, or support such as help with day-to-day tasks such as shopping or cleaning. Information is available on 'care at home' 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.

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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.

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.

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.

Action

- 1) Support will be available throughout the Dementia Journey to enable people to keep well, safe and independent in their own home for as long as possible.

Intended outcomes from the Strategy

People living with dementia will say:

- 1)) 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.
- 2) 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.

11. Safeguarding

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.

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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.

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.

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

Action

- 1) All agencies commissioned to provide support to people living with dementia will be required to understand the importance of 'safeguarding' and if they detect any issues will report it to the appropriate to the Council's Safeguarding Team.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) Professionals help me to plan ahead and manage the risks that are important to me.
- 2) People and services understand me - recognising and respecting what I could do and what I needed help with.

12. Active therapies, community assets

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 the Post Diagnostic Support Activity Group (peer support groups for people in the early stages of dementia) and Support Clubs (peer support groups for people with dementia and their carers). These are funded by the local authorities in Solihull. Additionally, activities such as 'Singing for the Brain' also offer therapeutic sessions to people with dementia and their carers.

Action

- 1) The weekly 'Post Diagnostic Support Activity Group' will continue to be commissioned by the Council.
- 2) Support Clubs will continue to be commissioned by the Council.
- 3) The Council's MyLife website will continue to advise people of activities available throughout the Borough.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) 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.
- 3) A comprehensive directory of services/active therapies will be available to me and my carer in a format I can use.
- 4) I will have access to support services, irrespective of my cultural background, and these will be culturally appropriate.

13. LIVING WELL WITH DEMENTIA

The Right Medication

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.

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

Action

- 1) The Memory Assessment Service will continue to assess people' potential suitability for dementia medication.

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Increasing Care (including End of Life Care)

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I will be given a trial of anticholinesterase medication (where appropriate) following my diagnosis with dementia.
- 2) I have access to 'non-drug' treatments when I exhibit behavioural and psychological symptoms of dementia.

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

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.

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 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.

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.

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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, Solihull Council will provide a free assessment of anyone who is providing substantial and regular care for someone.

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.

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, as well as a carers' support group in south Solihull.

Action

- 1) The various carer support services will continue to offer support to carers to enable them to have the support they need to continue in their caring role for as long as they feel able.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) 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.
- 3) Families and carers will feel better supported to understand and cope with caring.
- 4) My carer will have his/her own care plan and information about where to get help quickly when he/ she is struggling to cope.

15. Good care in general hospitals

Background

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. 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.

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.

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.

Action

- 1) All will be done to ensure that a person can remain in their own home and not need unnecessary admission to hospital.
- 2) Hospitals will continue to be encouraged to provide dementia friendly wards and have staff that have had dementia training and these staff will understand the importance of including family carers as an essential part of the care package while the person is in hospital.
- 3) Hospitals will continue to be encouraged to have effective discharge procedures to ensure that a person with dementia does not remain in hospital for any more time that is needed.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) I will be treated in dementia-friendly wards.

- 3) I will only be given antipsychotic and other tranquilliser medications where there are no safer alternatives.
- 4) I will be offered out-of-hospital services if needed to ensure that I am able to return home wherever possible.
- 5) My carer will be welcomed as an essential partner in care.

16. Living well with support and care

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.

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.

Action

- 1) Health and Social Care in Solihull will continue to work in a more integrated way to ensure that people get the 'right support at the right time'.
- 2) The Dementia Navigation Service will be available to support people to get the services they need at the right time.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) I have information about what services are available and the support that they can provide.

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

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

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

17. Managing changes in behaviour

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.

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.

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.

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Living Well with Dementia

Increasing Care (including End of Life Care)

Action

- 1) Birmingham and Solihull Mental Health Foundation Trust will continue to use best practice clinical guidelines for managing challenging behaviour and psychological symptoms in dementia (BPSD).

Intended outcomes from the Strategy

People living with dementia will say:

- 1) Wherever possible my behaviour will be managed by non-drug options.
- 2) 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.
- 3) 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.

18. Specialist mental health care

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).

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Increasing Care (including End of Life Care)

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.

Action

- 1) Birmingham and Solihull Mental Health Foundation Trust will continue to provide 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. They will ensure that people with dementia would be admitted to specialist inpatient care only when it is the most appropriate option, and admission would be for as short a duration as possible.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) I will only be admitted to mental health inpatient care if it is the most appropriate option.
- 2) 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.
- 3) 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.
- 4) I will be able to access specialist mental health services at the times I need them.

19. Living well with dementia in care homes

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.

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.

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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.

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.

The Care Fit for VIPs framework 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-centred 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.

Action

- 1) The Council will continue to work with Care Home Providers to improve the quality of care for people with dementia. The Care Home Providers will be sign-posted to the care Fit for VIPs Framework.
- 2) The Dementia Navigation Service will try to ensure that people with dementia who go into a Care Home to live take with them an up to date 'about me' document to help the staff at the Care Home to deal with person in a way that they would wish.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) 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.
- 2) 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.
- 3) 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.
- 4) I will have the option of dying in my care home setting if I choose.

20. End-of-life care

Background

The Department of Health's National End-of-Life Care Strategy (2008) 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:

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 ensuring comfort at end of life, manage their care at end of life, or because their service protocols dictated, or because families saw this as the only option.

Action

- 1) The Dementia Navigation Service will try to support people to make plans for the future including their wishes for their 'end of life' arrangements.

Intended outcomes from the Strategy

People living with dementia will say:

- 1) If I have dementia I will be assisted to complete a care plan including end-of-life plans.
- 2) I will be able to access end-of-life services in a consistent way across the area.
- 3) I will be supported by carers and professionals to help the person I care for to die peacefully in their preferred place.

Prevention and
Health Promotion

Recognition and
Identification

Assessment and
Diagnosis

Living Well with
Dementia

Increasing Care
(including End of
Life Care)

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, this will help commissioners, provider organisations and all those with an interest in dementia, to plan for the future.

Useful Sites

Birmingham and Solihull Mental Health Foundation Trust www.bsmhft.nhs.uk

Alzheimer's Society www.alzheimers.org.uk Alzheimer's Research UK
www.alzheimersresearchuk.org

Solihull Metropolitan Borough Council www.solihull.gov.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

Mental Health Partnerships www.mentalhealthpartnerships.com

Dementia Partnerships www.dementiapartnerships.com

