Cheshire West & Chester Dementia Strategy







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Foreword

We are delighted to present Cheshire West and Chester's Dementia Strategy, which covers the years 2017-2020. In it, we recognise the significance of a healthy lifestyle in preventing, delaying onset and living with dementia, as well as the importance of supporting carers, keeping them healthy in body and mind.

How well a person lives with dementia is reflective of the environment in which they live, work and socialise. Cheshire West and Chester's response to dementia is firmly rooted in and developed from the communities within the borough. We are committed to, and understand the importance of, having a programme of engagement that is ongoing. We will to listen to the views of local people, particularly those living with and affected by dementia in order to develop and shape our action plans. Our long term vision is to create 'Dementia Inclusive Communities'. To do this requires a change in attitudes and behaviours

towards dementia at all levels of society which reflect the challenges of an ageing population, people living longer and the impact of dementia.

Key stakeholders make up the membership of the Dementia Strategy Working Group. Our aim is for Cheshire West and Chester to be a place where everyone can lead a healthy and fulfilling life, including people with dementia and their carers. We want our residents to know that their borough is a place where people with dementia and those who care for them, are treated with dignity and respect, and get the help and support they need.



Councillor Samantha Dixon Leader of the Council, Chair of the Health and Wellbeing Board



Dr Chris RitchiesonChair of NHS West Cheshire CCG, Deputy
Chair of the Health and Wellbeing Board

Introduction and background

This strategy sets out the strategic framework for reducing the risk of dementia (or delaying its onset) and enabling people living with dementia and their carers to live well, in Cheshire West and Chester. We are clear about the responsibility that our organisations have to help shape and deliver a better model of health and social care for our residents who have, or may develop dementia and their carers, by building a collective response to the challenges.

Dementia is an umbrella term that describes the symptoms that occur when the brain is affected by certain diseases or conditions. These may be caused by a number of illnesses in which there is progressive deterioration, including a decline in memory, reasoning, communication skills and the ability to carry out daily activities.

Dementia is not just a disease of older age. People under the age of 65 with dementia symptoms are often described as 'younger people with dementia' or 'early-onset dementia' and make up more than 5% of all those with dementia. In addition, we recognise that often, people with dementia have other health conditions as well.

The emphasis in this strategy is on prevention, diagnosing well, living well, supporting well and planning well. The strategy will help us to make better decisions about how we:

- Value and understand those living with dementia and their families and carers
- Enable independent living for longer
- Raise awareness and understanding amongst our residents
- Use our existing assets and resources
- Design and provide services
- Encourage service providers to work together
- Encourage partnership working between services, service users and their families and carers

We will ensure that this strategy and its action plans do not stand alone, but are closely linked to other strategies and plans that also impact on living with dementia, for example, the Falls Prevention Strategy, the Carers Strategy and the Age Friendly Cities initiative. It will be evaluated and updated on a regular basis in light of progress, feedback (particularly from service users and their families/carers) and the evolving needs of our communities.



Where are we now?

Cheshire West and Chester has a population of approximately 333,900 and covers 350 square miles. It includes the historic city of Chester and the industrial and market towns of Ellesmere Port, Frodsham, Helsby, Malpas, Neston, Northwich and Winsford. About a third of the population lives in rural areas. According to the government's 'Indices of Deprivation', the overall quality of life is good for many residents. However, there are places where some communities experience multiple disadvantage.

Our population has an ageing profile, with the number of residents aged over 65 expected to increase by over 50 per cent by 2029 and those over 85 will more than double. In 2014/2015 (the latest data available), there were 2,780 people with a dementia diagnosis in Cheshire West and Chester.

Key lifestyle issues which we know to have an impact on dementia include smoking, unhealthy weight, unhealthy diet, physical activity and alcohol overconsumption:



Smoking levels have fallen markedly in recent decades and although our smoking rates are lower than the England average, they still remain a cause for concern. 13% of adults in Cheshire West and Chester currently smoke



Fstimated levels of adult excess weight (64.6%) are the same as the England average



Almost half of Chester West and Chester's adults do not eat the recommended amount of fruit and vegetables (5 a day) on a daily basis



Almost half of Cheshire West and Chester's adults do not exercise enough



Estimates indicate that a higher percentage of residents aged 16 and over drink alcohol compared to the England average

Our vision

Our vision for this strategy is:

'to create a borough which supports and is inclusive of people with dementia and their carers so they can enjoy the best possible quality of life and remain independent longer. We will do this by working with communities and those with, and affected by dementia, to improve support and services thereby ensuring there are opportunities to enable healthy, safe and fulfilling lives'

Our principles

1. Outcomes-focused

We want to put people living with, or affected by dementia at the heart of our strategy. We believe this will help to improve their health and social care outcomes, and ensure there is autonomy and accountability.

2. Emphasis on local action

This strategy has been developed with local people, in particular, those living with, or affected by dementia. The strategy is shaped by the issues that are important to them. Individuals living with dementia and those who care for them know what support they need and what needs to be done to improve services.

3. Innovation

We will find new ways of working that will serve people better. We will develop new models of support and service delivery through best practice, being creative and working across the health and social care system whilst ensuring a person centered approach.

4. Advocate for change

We will commit to challenging attitudes, behaviours and terminology whenever possible to ensure we continually progress our ambition to become a dementia inclusive borough. This includes workplaces as well as communities and public services.



Our approach

1. Prevention

We know that reducing the risk of dementia, or delaying the onset of dementia, is influenced by a wide range of lifestyle factors. Establishing and maintaining a healthy lifestyle is important to help lower the risk of dementia. Encouraging people (particularly in their forties and fifties) to reduce their risk of dementia will support them in living longer, healthier lives.

2. Partnership working

Dementia should not be seen as simply the symptoms a person exhibits, but must be seen in its

widest context, taking into account the persons' environment, the geography within which they live and the people who support them.

Many of the challenges that need to be addressed rely on the combined efforts of a variety of organisations in the public, private and voluntary sectors.

3. Evidence base

Decisions about services and programmes should be based upon the best available information and our strategy is based on our knowledge of local need as shown in the Joint

Strategic Needs Assessment. This ensures we make best use of resources, providing the best possible services and support.

4. Personal responsibility and empowerment

We want to develop a borough that fosters independence and dignity and ensures people living with dementia are valued. It is equally important to emphasise the benefits - socially, mentally and physically - that a healthy lifestyle has on preventing, or delaying the onset of dementia and enabling people with dementia to live well.



Prevention

Why is this a priority?

Reducing the risk of dementia, or delaying its onset, is influenced by a wide range of lifestyle factors. Establishing and maintaining a healthy lifestyle is important to help lower the risk of dementia, particularly vascular dementia. Encouraging people (particularly in their forties and fifties) to reduce their risk of dementia will support them in living longer, healthier lives.

In Cheshire West and Chester we want to enable people to have a healthier lifestyle and be better able to manage their own wellbeing and health. To achieve this, people need to be supported in remaining independent and are encouraged to be open to early interventions.

Alzheimer's disease is the most common form of dementia, followed by vascular dementia. Up to 50% of dementia cases may have a vascular component (vascular dementia or mixed dementia). Vascular dementia has the same risk factors as heart disease and stroke. Taking actions which promote prevention or early detection include leading a healthy lifestyle and effectively controlling or treating diabetes, high blood pressure and high cholesterol.

It is now believed that what is good for the heart is also good for the brain. There are a number of lifestyle factors that can increase the risk of dementia:

- A sedentary lifestyle (exercise in older people is associated with a slower rate of decline in memory and some thinking skills that occur with ageing)
- Excessive alcohol consumption (10% of the dementias are related to alcohol)
- Eating a poor diet high in saturated fat, sugar and salt and obesity in midlife

To reduce the risk of dementia or delay its onset, the National Institute for Health and Care Excellence (NICE) suggest the following lifestyle changes:

- Stop smoking
- Be more active
- Reduce alcohol consumption (only drink within NHS recommended limits)
- Improve diet
- Lose weight if necessary and maintain a healthy weight

Keeping the brain active and challenged throughout life may help reduce dementia risk. Keeping mentally active by learning new skills such as learning a second language, doing puzzles or joining clubs can be a good way to connect with other people and improve mental health and wellbeing. Improving social connectedness and being socially active can also help to reduce dementia risk by:

- Improving mood
- Relieving stress
- Reducing the risk of depression
- Reducing loneliness

Outcomes

People over 40 years of age lead a healthier lifestyle.

- 1. Percentage of adults that smoke
- 2. Physical activity in adults
- 3. Rate of alcohol related admissions to hospital
- 4. Excess weight in adults
- 5. Prevalence of depression



Diagnosing well

Why is this a priority?

In Cheshire West and Chester we want to see more people being diagnosed early and less diagnosed at a time of crisis; a crisis that might have been avoided if the diagnosis had been made earlier. We recognise that services may need to be redesigned, so that people with dementia are diagnosed in a timely manner and that they and their carers receive the right care and support, enabling them to live as well as possible with dementia.

Early diagnosis and intervention are key to improving quality of life. As diagnosis is the first step, it is important to ensure there is information and advice to help people exhibiting memory problems to present for assessment in a timely manner, usually to their local GP. It takes a lot of courage to express concerns about memory problems to a relative, friend or clinician. People who are worried about their memory or someone else's memory should have easy access to information about the early signs of dementia and signs of other conditions related to memory loss. Information about prevention strategies and support should be easily available. Support and good information should be available before and throughout the assessment process. A core aim of this strategy is therefore to ensure that effective information and support for pre-diagnosis and early diagnosis is available.

Working with our local GPs is essential to ensure that our residents are referred in a timely way for assessment and diagnosis and that people, who are worried about their symptoms, or their family/carers, are provided with relevant information and advice. GPs also require the necessary training to enable them to give a diagnosis of dementia. We also want to increase education and training regarding identification/screening, diagnosis and support, so that people with dementia receive care from staff who are appropriately trained in dementia care.

The drive to improve the diagnostic rate must not be seen as an end in itself; improving the support available to people once they have been given the diagnosis is equally as important. It is also important to recognise that contact with clinicians is not restricted to general practitioners; there are a range of other professionals, for example, opticians and pharmacists, who can be alerted to dementiarelated problems.

Outcomes

There is good quality support and information available to people from the pre diagnosis stage and throughout the diagnosis journey and people know where to access this.

- 1. New dementia diagnosis with blood test recorded between 12 months before and 6 months after entering on to the register
- **2**. People newly diagnosed with dementia and /or their carers receive written and verbal information about their condition, treatment and the support options in their local area

Living well

Why is this a priority?

In Cheshire West and Chester we want to help and encourage those who live with dementia to remain as independent as possible and continue to enjoy their usual activities in environments that are well designed and supportive of their needs. We recognise that most people with dementia live at home and are supported by friends, neighbours and families; they want to be able to continue to do things and go to the places they enjoy. We want to enable people who have been diagnosed with dementia to live as full a life as possible including maintaining their employment (those that are working at the time of diagnosis) and encourage our communities and workplaces to work together to help people to stay healthier for longer.

Across the borough we are striving to meet the Prime Minister's Challenge on Dementia which was launched in 2012. It focuses on developing communities where people are aware of and understand more about dementia, and enable those living with dementia to have a sense of belonging and of being a valued part of family, community and everyday life. Work with education (from primary schools to universities) is being encouraged to include dementia awareness in their work programmes, leading to the creation of dementia-friendly generations. The development of dementia inclusive communities is also a key element of the work required to meet this challenge and one which we have already seen great achievements being made locally.

Simple changes to existing services, and awareness raising for those who come into day-to-day contact with people with dementia, such as staff working in libraries or in leisure centres, can help people with dementia feel more confident and welcome in using Council and other services. Locally, we understand the importance of listening to people living with dementia, their families and carers, to inform and enable changes across all our services to:

- Raise awareness
- Challenge stigma
- Enable, inspire and facilitate dementia inclusive communities

We are committed to building on our achievements to date. These includes delivering dementia information

and awareness sessions that have resulted in the signing up of over 5,500 dementia friends, and the work undertaken with Tesco in Chester that has increased staff awareness and established the UK's first dementia-friendly checkout. Work is now being undertaken with our local high street banks and taxi businesses.

We will improve the buildings and environments from which services are delivered across the borough, ensuring any modernisation or planned design promotes accessibility. These improvements will help people living with dementia remain independent and socially connected. Local examples so far include Chester Storyhouse (the new cultural centre including theatre, cinema, library); Chester Northgate scheme (development including retail and leisure); Chester Bus Interchange; Baron's Quay (development in Northwich); and Weaver Square redevelopment (Northwich town centre).

Outcomes

Cheshire West and Chester is a dementia inclusive borough.

Indicators

- 1. People with dementia are enabled, with the involvement of their carers, to take part in activities based on individual interest and choice
- 2. Proportion of adult carers who have as much social contact as they would like
- 3. Carer- reported quality of life score

Supporting well

Why is this a priority?

Our mental and physical health are important whether we are living with a health condition or caring for someone with a health condition. Evidence tells us that isolation and depression are common amongst those living with dementia and those caring for someone with dementia. It is therefore vital to ensure we provide the right care and support at the right time and in the right manner to those living with dementia or their carers.

Many people are able to live well with dementia and continue to work following their diagnosis. In Cheshire West and Chester we believe that following a diagnosis, people who are still in employment should be supported to continue to work and engage in their regular activities for

as long as possible. We want people within the borough to have the support to build confidence and resilience and be better able to cope with the condition.

It is likely that many people in the Cheshire West and Chester area feel alone with their dementia, or their caring role. Our approach is to support person-centred relationships and this does not exclude people with dementia or their carers.

We also want to encourage discussions about life issues in the broadest sense, at the earliest opportunity. For example, alongside memory assessment services there should be information about legal and financial issues (including Power of Attorney and benefit entitlement), assistive technology to maintain independent living, and driving assessments.

In Cheshire West and Chester we want to establish a level of consistent support from GPs across the borough for carers, including ensuring carers are registered as such; and signposting to resources, advice and information. There is also a role for GPs in supporting people who may not have the benefit of close family carers or friends. This particularly relates to those people who may already feel some degree of isolation or exclusion, including those from Black Minority Ethnic (BME) and Lesbian, Gay, Bisexual and Transgender (LGBT) communities.

Our residents have told us that there needs to be more integration and communication between local services available to people with dementia and their carers.

Local research also tells us that improvements can be made in our hospitals. There needs to be a concerted effort to raise awareness and ensure there is a level of understanding of dementia amongst all staff coming into contact with people with dementia and their carers. In addition to working with staff, we want to be proactive in addressing care processes in hospitals to ensure all stages of care from assessment to discharge planning are dementia inclusive and therefore demonstrating good practice. We also need to ensure that people's physical health needs are addressed in the right place such as using hospital at home or step up beds to reduce the level of disorientation in a person who needs higher levels of care and support.

Knowing the population affected by dementia is an essential pre requisite to enable us to adequately resource services and provide the support needed as they progress through further stages. We are aware that this is an area of work that needs to be undertaken by all the major partners in the statutory and voluntary sector, with the involvement of those who are directly affected.

Lesbian, Gay, Bisexual, Transgender (LGBT) and dementia

Whilst LGBT people face the same health and care issues as everyone as they age, there are specific needs to be considered. The LGBT community is less likely to access services such as their GP early on. Older LGBT people may have grown up during a time when being gay was illegal or LGBT was considered an illness, which could have resulted in a distrust of disclosing sexual orientation and gender identity to professionals.

LGBT people are more likely to be estranged from their family and live alone; formal care is likely to be very important to their quality of life. There are, however, fears of being in residential care or having a carer in their own home, with the perception that their identity will be made invisible. If they are transitioning or have transitioned, there may be needs around medication and an understanding of their own transition status as they become increasingly affected by dementia.

We need to ensure staff are aware of the wider issues and trained on equality and diversity. Services that are being delivered and the support offered to our residents must be equitable, respectful and LGBT friendly.

Outcomes

Those living with and affected by dementia are able to lead fulfilling lives and live independently for longer.

People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing

People with dementia receive care from staff appropriately trained in dementia care

People with dementia and their carers get the correct assessments and entitlements

- **1.** Evidence of local arrangements to ensure services are tailored to an individual's needs
- **2**. Proportion of people with dementia whose individual needs are assessed and whose care plan states how these will be addressed
- **3.** Proportion of carers who are satisfied with the services they and the person they care for have received from Adult Social Care in the last 12 months

- 4. Proportion of carers who feel encouraged and supported in their caring role
- 5. Proportion of carers whose health has been affected by their caring role in the last 12 months
- **6**. Number of Dementia Champions across the borough
- 7. Number of people living with dementia using assistive technology

Planning well

Why is this a priority?

Following a diagnosis of dementia, putting legal, financial and end-of-life plans in place is one of the most important steps to take. The sooner plans are established, the better prepared the person with dementia and their carers and family will be.

Creating a plan for the future in the early stage of the disease can be empowering, allowing the person with dementia to participate in making decisions that help family and friends know their wishes. They can then focus on enjoying their life moving forward.

We want to ensure planning for the future starts early, to ensure the person with dementia is still able to make decisions and is enabled and supported to express their wishes at every step. Involving the family and managing their expectations is part of good quality care.

Outcomes

People with dementia are supported to put legal, financial and end-of-life plans in place.

- 1. Evidence of local protocols on the discussion of advance decision- making
- **2**. Proportion of people with dementia, while they have capacity, and their carer/s, who are given the opportunity to discuss with health and social care professionals about the use of:
 - Advance statements
 - Advance decisions to refuse treatment
 - Lasting Power of Attorney
 - Preferred Priorities of Care



Performance framework for the strategy

Joint scorecard

Key statistical data monitored regularly by the Dementia Strategy Working Group and the Health and Wellbeing Board

Exception reporting

Statistical data which is escalated to the Health and Wellbeing Board requiring review or action

Health and wellbeing partnerships updates Updates will form part of a report that is presented at every Health and Wellbeing Board meeting

Themed discussions

The Dementia Strategy Working Group will have a rolling programme focusing on key issues which will generate challenge and actions

Peer review

The Dementia Strategy Working Group will seek to enhance the performance of the strategy and share learning

The voices of local people, service users, carers and wider partnership

There will be regular opportunities for groups and communities to feedback their own views and experiences



Conclusion

This strategy sets out our ambition to create a place where people who are living with or affected by dementia can thrive. We hope that people will be less fearful of dementia and know it is possible to live well with dementia. We also know that by adopting a healthy lifestyle we can delay or even prevent the onset of dementia. By including a focus on healthy lifestyles, more people can enjoy more active and fulfilling lives.

The strategy and action plans will develop as goals are achieved and circumstances change. We will be responsive to the information we gain through the

continual involvement of organisations, groups and local people, particularly those living with and affected by dementia.

The indicators will use existing performance measures and may require the creation of new performance measures which align to the outcomes identified within the strategy. The local Dementia Strategy Working Group will review the action plans and the outcome measures at least annually. Progress and updates will also be provided regularly to the Health and Wellbeing Board.

Membership

The Dementia Strategy Group is chaired by a Consultant in Public Health and has representatives from the following organisations and groups:

- Age UK
- Alzheimer's Society
- Cheshire and Wirral Partnership NHS Foundation Trust

- Cheshire West and Chester Council
- Countess of Chester NHS Foundation Trust Hospital
- Deafness Support Network
- Healthwatch
- NHS Vale Royal Clinical Commissioning Group
- NHS West Cheshire Clinical Commissioning Group
- Service User Representative























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