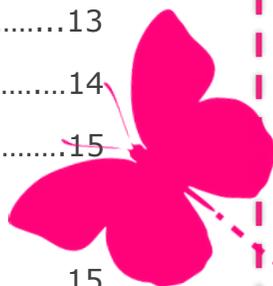


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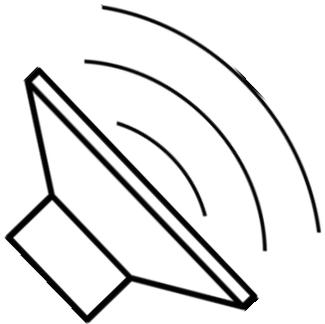
ACKNOWLEDGMENTS



We are very grateful to the residents of West Sussex, our partners, staff and other stakeholders who were instrumental in the successful development of this strategy through their participation and feedback.

Particular thanks goes to Alzheimer’s Society’s Chichester & Bognor Positive Thinkers, Horsham Rusty Brains and Worthing Town Cryers. Age UK’s K2 Club, Sangam Women’s Group and Carers Support West Sussex East Grinstead carers group.

FOREWARD



With the ageing population of the county expected to rise exponentially in the next 10 years, a timely diagnosis for those with dementia is vital not only for them, but also for their family and friends. A timely diagnosis enables them to maximise control over their lives by planning ahead and accessing support to ensure that they can enjoy an active and independent life for as long as possible.

The County Council and the Clinical Commissioning Group are resolved to make West Sussex the best place to live well with dementia. This strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to delivery of services, we must ensure that there is adequate and meaningful provision to help and support those with dementia, as well as their family and friends.

Promoting self-care and self-empowerment is often a primary requirement for those who want to stay in their own homes. Family and friend carers are influential in supporting those living with dementia and it is therefore key that we support them in their caring role. Carers tell us that their wellbeing is as much about their experience of the health and social care system as it is about services for them. We need the system not only to recognise carers, but to listen to them and involve them as appropriate.

I hope you will find this strategy informative and of interest. I believe that the more we engage and plan together with those who need our support, the better quality of life will be achieved for them which for me is of paramount importance.

Amanda Jupp

Chair – West Sussex Health and Wellbeing Board Cabinet Member for Adults and Health West Sussex County Council



INTRODUCTION

This strategy has been developed by the West Sussex County Council and Clinical Commissioning Group in partnership with our stakeholders and includes direct input from people with the lived experience of dementia. It builds on the progress of our first dementia strategy and the progress that has been made. The Strategy sits within the context of national and local policies, guidance and legislation.

The primary audience for the West Sussex Joint Dementia Strategy 2020-23 is the Health & Wellbeing Board, local leaders, officers, commissioners and providers responsible for its delivery. However, care has been taken to make the strategy as accessible as possible for residents, staff and partners in understanding priorities and how all partners can contribute to them.

Purpose of the strategy

To build on the work of the 2014-19 Dementia Framework, refresh our goals and set out the plan for action for the next three years.

Understanding the challenges

There are 3 main challenges we face:

1. An ageing population. Although dementia is not a natural part of growing older, it is more prevalent in people over the age of 65. The population of older people is set to rise in the next 10 years and the highest increase will be in people over aged 80 (60%). Older people are more likely to have other significant and life limiting chronic conditions, this will result in the need for an increase in Health and Social Care spending where there is already a reduction in public funding.

2. Timely diagnosis can enable people to maximize control over their lives, plan ahead and access support that can help them live well with the condition. The increase in the number of people with dementia is however impacting on how quickly people receive their diagnosis.
3. Recruitment and capacity challenges within the care market that is impacting on the availability of good dementia care.

OUR VISION

To improve the health and wellbeing of local people and for those people who develop dementia to be supported to maintain their independence for as long as possible.

For people with dementia and their families and carers to:

- receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice;
- have access to timely, skilled and well-coordinated support throughout their journey;
- receive care and support that focuses on an individual's strengths and looks to promote their wellbeing;
- be central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

For there to be supportive communities, where people feel able to participate in community life without stigma.

Where we are now

In 2018, a full review of the Dementia Framework West Sussex 2014-19 took place. It was led by the County Council and all three Clinical Commissioning Groups and included a public engagement with around 400 different people and organisations. The review suggested there had been some good progress made in the last five years but there was still quite a lot left to do to improve the experience of people living with dementia and their families. This Strategy sets out what we plan to do about this.

How we will get there

To work closely with health, social care, community, voluntary, private providers and local people. Work to a delivery plan which will support the goals of this strategy and will include clear measures and points of review at regular intervals.

Meeting the challenges faced needs a commitment and willingness to innovation and learning. There needs to be a focus on community led support and prevention and for Adults Services to look at enabling an individual to see the value they bring and the resources around them rather than focusing on any negative characteristics.

National and Local Context

This strategy is based on relevant national and local policy, guidance and legislation. The **NHS Five Year Forward View** and the Department of Health **Prime Minister's challenge on Dementia 2020** set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers.

Ageing well and caring for people with dementia are both key priorities in the **NHS Long Term Plan**. The Plan focuses on the need for people to be helped to stay well and to manage their own health, possibly with the use of digital tools. It also calls for a transformed workforce with a more varied and richer skill mix.

Care Act 2014 created a new legislative framework for Adult Social Care. Local Authorities have new functions to ensure people living in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs. People should also have a range of high quality, appropriate services to choose from.

Five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life. (See Appendix A of full strategy.)

West Sussex Plan – Priorities around Independence for Later Life.

Sussex Health and Care Partnership Strategic Delivery Plan – Appendix - West Sussex Place Based Response to the Long-Term Plan October 2019.

Joint Commitment to Carers 2015-20 – states the main priority areas for family and friend carers for health and social care. This document to be refreshed over the course of this strategy.

West Sussex Joint Health & Wellbeing Strategy 2019-24 - the Health and Wellbeing Board's vision, goals and ways in which it will work to improve the health and wellbeing for all residents in West Sussex. It is anticipated this document will be refreshed over the course of this strategy.

Adult Social Care in West Sussex – Our vision and strategy 2019-21 - sets out how we will continue to work together to build on the good progress we have made to implement a strength-based community-led approach, focusing on prevention and reablement, supporting family and friend carers, and working towards the integration of services.

Sussex Community NHS Foundation Trust Dementia Strategy

Western Sussex Hospitals NHS Trust Dementia Strategy

THE NATIONAL PICTURE

Most people associate dementia with older people but there are more than **40,000 younger people in the UK living with dementia under the age of 65** years who are affected by this condition.

Note: The Lancet Commission presents a new life-course model showing that 35% of risk factors are modifiable.

850,000 people living with dementia in the UK⁴

By 2025 – Over one million people could have dementia in the UK

By 2050 the figure will exceed 2 million

THE LOCAL PICTURE

How dementia might look in next 10 years:

	2020	2025	2030
Early onset (under 65)	500	550	600
Late onset	15,700	18,250	21,300
Total dementia	16,650	19,350	22,450

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800
TOTALS	16,650	19,350	22,450

People with mild symptoms will be able to remain independent in their own home. For some people in the 'Moderate' and those in the 'Severe' categories, more support and perhaps long-term care may likely be needed.

No. People with Down's Syndrome in West Sussex likely to have dementia

Age in Years	2009	2015	2020	2025	2030
45 -54	9	10	10	10	8
55-64	18	18	18	21	21
Sub-Total: 35 - 64	27	28	28	31	29
65 and over	1	2	2	2	2
TOTAL	28	30	30	33	31

Source:
www.pansi.org.uk/index
 and
www.poppi.org.uk/index

Many people with dementia also live with one or more other health conditions.

THE ECONOMIC COST

There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn¹⁰.

	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

The total costs here include all those associated with supporting older people living with dementia rather than the extra costs attributable specifically to dementia itself.



The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition, half of this number are aged over 85. There is a total weekly net cost of £290,000 and much of this cost (85%) is accountable for by long term residential and nursing care.

The total net spend on residential and nursing care for people over age 85 requiring memory and cognition support is around £128,000 each week. The number of people in this age group is expected to rise by 60% in the next 10 years and resources will therefore need to focus on keeping people at home for longer and away from more expensive long-term care.

Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m*.

The need to ensure we continue to improve services to meet the needs of people affected by dementia is a high priority. However, the County Council and Clinical Commissioning Group are working with reduced public funding. The strategy has therefore been developed within the context of these financial restraints.

*People aged 65+ with dementia that are short stays (1 night or less) is estimated to be £1.6m. 2017 data

THE DEMENTIA WELL PATHWAY

The Dementia Well Pathway has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and carers from prevention to end of life care. This strategy has used the dementia well Pathway as a framework with which to present its goals for the next three years.

PREVENTING WELL
Risk of dementia is minimised

DIAGNOSING WELL
Timely, accurate diagnosis, care plan and review within first year

SUPPORTING WELL
Safe high-quality health & social care for people with dementia and carers

LIVING WELL
To live normally in safe and accepting communities

DYING WELL
To die with dignity in the place of your choosing.

The Dementia Well Pathway has been used as a foundation for developing the goals of the West Sussex Joint Dementia Strategy 2020-23.

Preventing Well

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves."

There are some risk factors that you cannot change but research suggests up to one in three cases of dementia are preventable. Risk factors that may be preventable include:

Diabetes (type 2), high alcohol intake, lack of exercise, obesity, poor physical health, smoking. Hearing loss, hypertension, Depression and social isolation are other factors that could contribute.

Key issues & challenges

Green spaces in West Sussex providing opportunities for people to get more physically active. **Risk factors across the lifecourse approach as identified in the Joint Health & Wellbeing Strategy. For example, educational attainment, physical inactivity etc. **Information about the early signs and symptoms of dementia and positive messages about the benefits of diagnosis to encourage people to access a diagnosis. **Low diagnosis rates in people from black and ethnic minority groups (BAME). **Improved access to information about dementia for people with learning disabilities. **Greater risk to family and friend carers of loneliness and physical and mental health problems.

DIAGNOSING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves."

A diagnosis of dementia provides the opportunity to be able to plan ahead while the person is still able to make important decisions. In West Sussex the pathway to diagnosis is normally through the GP who will refer the person to the Dementia Assessment Service (DAS) or Memory Assessment Service (MAS) once all reversible causes of cognitive decline are ruled out.

The MAS/DAS will provide a quality diagnosis and follow-up support for the patient and their family and friend carer. At this point, a care plan will be developed which provides an opportunity for the person to be able to draw on their own strengths and assets and identify where additional support is required.

The Prime Minister's Challenge recommends that people receiving a diagnosis should have a named coordinator with a good understanding of the person and their needs along with how to navigate the health and social care system. In West Sussex, this is normally the person's GP.

Key issues & challenges

Fear of stigma preventing someone accessing a diagnosis, more information about benefits needed. **Early signs of dementia not being recognised in people with learning disabilities. **Long waits to diagnosis. **Low rates of diagnosis in people from Black Asian & Minority Ethnic Communities (BAME) and people with Alcohol Related Dementia. **Accessing information and advice after diagnosis. **A system that is complicated and disjointed where people can get 'lost' in the system. **Care plans not being shared with all those involved in the person's care. **The need for services to stay connected to the person living with dementia.

SUPPORTING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia and their family and friend carers receive high quality care and support throughout their journey from health and social care staff skilled in good dementia care that is individual to the needs of the person with dementia."

The best place for someone living with dementia is to remain at home independently for as long as possible but the progressive nature of dementia means that often people will develop increasingly complex needs. Suitable housing and assistance to live at home is therefore necessary.

It is important there is joined up support when a need arises. Adult Social Care, Proactive Care and Specialist Dementia Services are working together to help achieve this by working together, shifting the balance of care away from reactive crisis intervention to independent health and wellbeing. There also needs to be a focus on community led support and prevention and for Adults Services to look at enabling an individual to see the value they bring and the resources around them rather than focusing on any negative characteristics.

As the dementia progresses, some extra care and support to enable the person to live at home may be necessary. WSCC continues to actively engage and support the market development of care and support at home providers and focus on building opportunities for developing local markets. Extra Care Housing can also be a good solution as it offers the security of having staff on hand and the Council currently commission 12 out of the 13 Extra Care Schemes in the County.

For people who can no longer live at home, the Council has a responsibility for ensuring there is an offer of good quality residential and nursing care and sufficiency of supply. Support should be easily accessible for the person and their families and carers to be able to make the right decision about their future care planning and how it will be funded.

Services such as Dementia Crisis, Living Well with Dementia, Community Dementia Matrons and Admiral Nurses are working hard to support people at an increased risk of an unplanned hospital admission. A stay in hospital for someone with dementia can be traumatic and confusing and there can be issues with eating, drinking and pain relief. For those people going into hospital, the Home from Hospital, Take Home & Settle and Relative Support services provide support for the person and their family.

Key issues & Challenges

Lack of clarity about eligibility for dementia services.**People with dementia often have more than one health condition but health services do not always work together.**Services designed at keeping people at home are stretched and struggle to meet demand.**People with dementia from Lesbian, gay, bisexual and transgender + (LGBT+) communities can feel mainstream services do not meet their needs.**Lack of 24/7 crisis support - Falls and fractures are common in people with dementia.**Unplanned admissions to hospital, longer stays and delays in discharge.**Insufficient capacity within care market and challenges with recruiting care staff.**Overstretched resources.**Gaps in staff training and often lack of confidence in supporting someone with complex and challenging needs.

LIVING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia are supported to live well with dementia by enabling them to: Stay socially active; Keep healthy and well; Access safe and welcoming communities that are responsive to the needs of people with dementia; Have access to quality information about dementia and the support available such as community activities, leisure and transport; Receive support to engage in meaningful activity, doing something that people enjoy or are interested in; and for family and friend carers to receive the support they need to be able to continue in their valuable caring role."

Breaking down the stigma of dementia and support are key to ensuring people with dementia can live meaningful and satisfying lives. Dementia Friendly Communities can help people to access their local communities and reduce the risk of social isolation. Local Dementia Action Alliances (LDAA) focus on changing public attitudes through the creation of dementia friendly communities. In West Sussex there are 10 LDAA's with a membership of local businesses, community groups, faith groups etc.

Support for the family and friend carer is essential and the Care Act 2015 gave the council enhanced duties towards carers. In West Sussex, there is a consistent offer of support, information and guidance to all carers delivered by Carers Support West Sussex. This provides a gateway to all other carers support services throughout the County. There is a diverse set of services for carers provided by the local authority, clinical, voluntary and community sector providers.

There needs to be a community led support approach to help meet the challenges faced and willingness to innovation and learning. A good example of this is new community led support talk locals and drop-ins.

In West Sussex, there is a universal offer of information and advice for people with dementia and their families from Alzheimer's Society's Dementia Support Service along with a county-wide information and advice service commissioned by Public Health. A dementia zone on the West Sussex Connect To Support website provides information about dementia and local support.

Key Issues & Challenges

Family and friend carers becoming socially isolated.**Lack of flexible breaks for carers.**Historically low uptake of services from BAME communities.**Accessing suitable activities for people from LGBT+ community.**Age appropriate activities for younger people with dementia.**Sustainable dementia friendly communities.**Transport**Local activities.**Support to access mainstream activities.

DYING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people with dementia and their families are supported to plan ahead, receive good end of life care and are able to die in accordance with their wishes."

All people with dementia should be given the opportunity to plan for their future care as early on as possible. The person with dementia and their family and friend carer should be involved in any decisions about end of life care, this reduces the likelihood that difficult and emotional decisions have to be made in a crisis and/or when the person's wishes can no longer be taken into account. Where necessary, advocates need to be identified to support the person with health and welfare decision-making to ensure their wishes are reflected. In West Sussex, the Clinical Commissioning Group along with health services and local hospices have endorsed an Advance Care Plan called 'Planning Future Care'. This is being used to identify people's wishes and preferences for future care.

People nearing the end of life need to receive coordinated compassionate care that is individual to their needs. This includes palliative care and bereavement support for the family. Care should be provided by skilled, trained and compassionate staff and family and friend carers throughout their life journey. In Coastal West Sussex, the End of Life Care Hub (ECHO) works proactively to support people in the last year of their life and provides a more responsive, proactive and individual offer of care.

Key issues & Challenges

People with dementia not supported to plan for their future care soon after diagnosis.**Advance care plans not being shared with all those involved in the person's care.**Hospital staff unaware of the person's end of life wishes.** People dying away from their usual place of residence or a place not of their choosing.**Lack of bereavement support.

Dementia in Different Groups of People

Early Onset Dementia

Younger people with dementia (under the age of 65) face different issues to someone older. There is often a long wait to diagnosis as other conditions are explored and support designed for older people is often unsuitable for someone younger and more active. This means that this group of people can often find themselves feeling isolated.

Lesbian, gay, bisexual and transgender + (LGBT+) and Dementia

Older people from this community are less likely to have the support from family members and children and they often live on their own. Many people fear that mainstream care services will not be willing, or are not able to understand how to meet their needs.

Learning Disabilities and Dementia

People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome. Symptoms are often not realised as being dementia related because they can present differently. In West Sussex, the pathway to diagnosis is patchy.

Black Asian & Minority Ethnic Communities (BAME) and Dementia

Among the UK's BAME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.

Alcohol Related Dementia

More common in people in their 40s and 50s it comprises about 10% of cases of Early Onset Dementia. The condition is poorly understood, and patients struggle with the 'double stigma' of dementia and alcohol addiction. There is a lack of community services and clear pathways to support.

OUR GOALS

Preventing Well

**People live, work and play in environments that promote health and wellbeing and support them to live healthy lives and for individuals, families, friends and communities to be connected. **There is a greater awareness of factors increasing the risk of dementia and what can be done to reduce them. **Early intervention and ongoing support for hearing loss.



THE DEMENTIA WELL PATHWAY

This strategy is based on the Dementia Well Pathway's five elements from the Prime Minister's Challenge on Dementia

Diagnosing Well

**People recognise the early signs of dementia and know what to do to receive a diagnosis. **All groups of people to receive a timely diagnosis. **Improved access to information and advice. **Improved access to good quality joined up support following diagnosis. **People have the opportunity to plan for the future.



Supporting Well

**For people to be enabled to live at home. **For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia. **Approaches to care and support that are individual to the person's needs. **Compassionate care and support from staff skilled in dementia. **Dementia friendly health and care settings. **The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support.



Living Well

**People to have access to a range of affordable flexible activities that reflects their interests and needs. **There is a whole community response to living well with dementia in safe and enabling communities. **People can maintain and develop their relationships and be able to contribute to their community. **Carers of people with dementia are able to access support as needed and feel able to continue with their caring role.



Dying Well

**People living with dementia together with their families and family and friend carers are enabled to make decisions about their future health care. **People are supported to die with dignity in a place of their choice. **Families and carers are provided with timely, coordinated support before death, at the time of death and bereavement.

A JOINT STRATEGIC APPROACH TO DEMENTIA

The range of support for people with dementia is patchy; people often get lost trying to navigate an array of information and services. We know people living with dementia face a variety of challenges and have a range of needs; so, to achieve our vision it is key that organisations work together to collectively transform the approach to dementia in West Sussex.

This document represents the combined views of many partners, each of whom is committed to working together to make life better for people affected by dementia.



MONITORING DELIVERY & IMPACT ACROSS THE PATHWAY

The delivery plan sets out how West Sussex County Council and the Clinical Commissioning Group plan to monitor the progress being made with the goals set out above and looks at what can be achieved with current resources. An additional section has been included that looks at what can be achieved with a little and much more funding.

It is vital that we assess whether this strategy is making a demonstrable difference to the experience of people living with dementia and their family and friend carers. We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this strategy. We will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.