# WEST SUSSEX

# JOINT DEMENTIA STRATEGY 2020 TO 2023

## Developed in partnership with

## West Sussex County Council and

## NHS West Sussex Clinical Commissioning Group

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## ACKNOWLEDGEMENTS

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 go to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains, Crawley Forward Thinking Group, Mid Sussex Dementia Forum and Worthing Town Cryers, Age UK West Sussex Cando@K2, 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, where this is appropriate, 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 NHS 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 is West Sussex's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out our commitments, the strategy provides a framework for further action to ensure the realisation of our shared vision for dementia in West Sussex.

This strategy has been developed in partnership with Health, Social Care, Councils and Community and Voluntary providers. It is based on the findings of the 2018 review of the Dementia Framework West Sussex 2014-19 and includes direct input from people with dementia and their families and carers. The Strategy sits within the context of national and local policies, guidance and legislation.

### What is dementia

The term dementia describes a set of symptoms including memory loss, mood changes, and problems with communications and reasoning. It is caused by diseases of the brain, the most common being Alzheimer's.

Dementia is not a natural part of growing old and, although dementia is more common in people over the age of 65, the condition can also be found in younger people.

### Purpose of the strategy

Findings from a review of the current Dementia Strategy, the Dementia Framework 2014-19 in 2018, showed there had been improvement.

In 2014 the diagnosis rate for West Sussex was just 46%, this has risen and is now around 66%; there has been an improved offer of post-diagnostic support for the individual and their family carers from Dementia Advisers, Dementia Support Workers, carer support services. Our communities have become more dementia friendly places to live and there are now 10 Local Dementia Friendly Community Groups with 300 members committed to becoming dementia friendly businesses and organisations.

It was identified though that there is still more that needs to be done to improve the experience of people affected by dementia. This Strategy sets out how we plan to build on the progress that has been made and address the gaps.

This new Strategy refreshes our goals so that they better reflect the current financial climate, the changing needs of the population together with new local and national plans and guidance, policies and legislation. The Strategy aims to set out the plan for action over the next three years by the County Council and the Clinical Commissioning Group (CCG) in order to inform the planning, commissioning and provision of services.

This Strategy is not a stand-alone document but sets the direction of travel and complements the many strategies and plans we already have, under one clear vision and purpose.

**How we will get there**

- There needs to be a collaborative approach across health, social care, community, voluntary and private providers, together with local people to achieve our objectives.
- A focus on community-led support is necessary to achieve our ambitions together with a willingness to innovation and learning.
- People living with dementia need to be enabled to live independently for as long as possible and supported to see the value they bring and resources around them rather than focusing on any negative characteristics.
- The strategy will be supported by a delivery plan with clear measures and points of review to ensure that the intended aims are being achieved. The delivery plan includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved in commissioned services within the current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available in the future.

**Audience for the strategy**

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.

## UNDERSTANDING THE CHALLENGE

There are four main challenges we must address over the course of this strategy.

1. An ageing population. The prevalence of dementia is set to rise exponentially over the next ten years with people often having other significant and life-limiting chronic conditions. This will place a huge demand on capacity within services.
2. Timely diagnosis and support. There can be long waits to diagnosis and there are particular issues for younger people, people with learning disabilities and people from black, ethnic and minority groups.
3. A consistent offer of information and advice and support. Information and advice and support is normally provided at diagnosis but people need to be

able to access support and coordinated information and advice at every stage in their journey.

4. Challenges within the care market. These are around recruiting and retaining health and social care staff skilled in delivering good quality dementia care and reductions in the number of care home beds registered to support people with dementia.

## STRATEGY DEVELOPMENT PROCESS

- Review of the Dementia Framework West Sussex
- 2014-19 including engagement with wider stakeholders.
- Identification of key issues and emerging themes
- Multi-agency task & finish group to drive strategy
- Engagement with people with lived experience
- Themed sub groups
- Draft strategy consultation with stakeholders
- Strategy update and sign-off

## 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 and enjoy a good quality of life for as long as possible.

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

For people with dementia and their families and carers to:

- receive high quality, compassionate care and support, with timely diagnosis, where this is appropriate, and to 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.

## 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. These are just a few of the achievements that were identified as part of the review:

- West Sussex Dementia Learning & Development Framework. An on-line resource to signpost people to free learning resources.
- All hospital staff trained in dementia awareness, care and support. John's Campaign and open visiting hours are just a few of the initiatives taking place in all our hospitals to improve patient outcomes.
- Dementia Zone on the Council's Connect To Support website providing information about dementia and links to support.
- Learning and training for family and friend carers through Alzheimer's Society and Carers Support West Sussex.
- More people receiving a diagnosis and follow-up support. Around 20% more people are now receiving a diagnosis of dementia and the number of people registered with GP's has increased by 28%.
- A more dementia-friendly West Sussex. 10 Local Dementia Friendly Community Groups in West Sussex and around 300 members.
- Libraries running Memory Management Ticket; Reminiscence Collections, dementia awareness drop-ins and Reading Well Books on Prescription for dementia.
- Weekend away short breaks for younger people living with dementia run twice a year.

However, there is a significant number of people living in West Sussex with undiagnosed dementia and many people who feel unsupported following diagnosis. This document sets out what we plan to do about this.

## IDENTIFIED GAPS

Age appropriate support needed for the whole family

Age and stage Daytime activities

Gaps in services designed for physical health and dementia

Transport issues

Lack of local activities and flexible respite

Finding residential care

Lack of planning for future including contingencies

Diagnosis and support for Learning Disabilities

Engaging with people from minority groups

Uncoordinated and fragmented information and advice

Information not being shared

## THE NATIONAL PICTURE

### Table 1

### Projected number of older people living with dementia 2019-2040 England

| SEVERITY | 2019 | 2020 | 2025 | 2030 | 2040 | %change |
|---|---|---|---|---|---|---|
| **Mild** | 107,100 | 108,300 | 118,900 | 136,100 | 166,700 | 56% |
| **Moderate** | 206,300 | 198,900 | 210,100 | 235,600 | 276,100 | 34% |
| **Severe** | 434,600 | 461,900 | 569,400 | 674,400 | 909,600 | 109% |
| **TOTAL** | **748,000** | **769,200** | **898,500** | **1,046,100** | **1,352,400** | **81%** |

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

850,000 people living with dementia in the UK (reference)[1]

By 2050 – It is expected the number of people with dementia in the UK could exceed two million.

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

42,000 people living with dementia are under the age of 65

Many people with dementia also live with one or more other health conditions. Studies have shown that:

- 41 per cent have high blood pressure
- 32 per cent have depression
- 27 per cent have heart disease
- 18 per cent have had a stroke or transient ischemic attack (mini stroke)
- 13 per cent have diabetes (Barnett et al, 2012). (reference)[2]

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

## THE LOCAL PICTURE

**Table 2**

**The population of people over age 65 is set to rise in the next 10 years:**

| Age | 2020 | 2025 | 2030 |
|---|---|---|---|
| **65-69 years** | 49,583 | 54,905 | 64,058 |
| **70-79 years** | 91,222 | 99,744 | 100,271 |
| **80-89 years** | 49,133 | 58,554 | 72,611 |
| **90+ years** | 12,836 | 16,674 | 20,752 |

The highest increase is in people aged over 80.

**West Sussex people aged 65 and over by ethnic group year 2011 (figures taken from 2011 census)**

| | |
|---|---|
| Other ethnic group | 163 |
| Black/African/Caribbean/Black British | 246 |
| Asian/Asian British | 1555 |
| Mixed multiple ethnic groups | 514 |

**Proportion of people by District aged 65 and over from all ethnic groups:**

Adur 6%, Arun 12%, Chichester 7%, Crawley 42%, Horsham 8%,
Mid Sussex 13%, Worthing 11%

**How dementia might look in next 10 years**

**Table 3 – Age of onset**

| Age of onset | 2020 | 2025 | 2030 |
|---|---|---|---|
| **Early onset (under 65)** | 500 | 550 | 600 |
| **Late onset** | 16,150 | 18,800 | 21,850 |
| **TOTAL DEMENTIA** | **16,650** | **19,350** | **22,450** |

**Table 4 – Severity of dementia**

| Severity of dementia | 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 should 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.

**Table 5**

**The No. of People with Down's Syndrome in West Sussex likely to have dementia by 2030**

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

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

**Dementia sub-types**

| | |
|---|---|
| Alzheimer's | 62% |
| Vascular | 17% |
| Mixed | 10% |
| With Lewy Bodies | 4% |
| Frontotemporal | 2% |
| Parkinson's | 2% |
| Other | 3% |

This strategy is based on the following relevant national and local policy, guidance and legislation:

## NATIONAL CONTEXT

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 guided by 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 who live in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs and to have a range of provision of high quality, appropriate services to choose from. The Care Act also gave carers a legal right to assessment and support.

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)

## LOCAL CONTEXT

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 will be refreshed during the course of this Strategy.

West Sussex Joint Health & Wellbeing Strategy 2019-24 sets out 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.

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. It is anticipated this document will be refreshed during the course of this Strategy.

Sussex Community NHS Foundation Trust Dementia Strategy.

Western Sussex Hospitals NHS Trust Dementia Strategy

## THE ECONOMIC COST

The number of people with dementia is set to rise exponentially over the next ten years with many people also living with one or more other health conditions. There is a considerable economic cost associated with dementia and this will place a huge demand on capacity within services where there has already been a reduction in public funding.

In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn (reference)[3].

Social care is projected to account for a slightly larger proportion of the total costs, and unpaid care a slightly lower proportion, in 2030 than in 2019. The proportion of older people living with dementia who have severe dementia is projected to rise in the next decade (see 'Local Picture' section). The likelihood of living in a care home increases with severity of dementia, which means that this rise will impact on the cost of social care over time.

| | |
|---|---|
| Healthcare | £4.3bn (17%) |
| Social care | £10.3bn (39%) |
| Informal care | £11.6bn (44%) |

**Table 6**

**West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)(reference)[4]**

| | 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.

Around a third of projected costs of dementia are saved through the care of family and friend carers (ie unpaid care). This is set to rise by 68% over next 10 years.

The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition at an average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long term residential and nursing care.

More than half the number of people in this group are over the age of 85 with a total weekly net spend on residential and nursing care of around £128,000. With numbers of people in this age group expected to rise by 60% in the next 10 years, resources will 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. It will be necessary to ensure there is continued investment in the services designed to provide a timely diagnosis and ongoing care and support to ensure they can grow in line with the rise in demand. It is also important to continue to look at how we can: enable people to reduce the modifiable risks of dementia; redesign and transform services to focus resources on keeping people independent for longer; support family and friend carers in their caring role and support a community-led approach to enabling people to live well with dementia.

A delivery plan underpins this strategy and includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved within current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available over the course of the Strategy.

*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. The Pathway puts the individual and their family and friend carer at the centre of service development and implementation.

**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 well in safe and accepting communities.

**DYING WELL**

To die with dignity in the place of your choosing.

### Family & Friend Carers

It is essential that family and friend carers are central across the pathway. In line with the Joint Commitment to Carers this Strategy will ensure family and friend carers:

- are identified and supported as early as possible.
- are considered partners in the care of the person with dementia.
- are offered an assessment of their need and support that is individual to them.
- have good access to information and advice about dementia in a format that is right for them. from the time before diagnosis all the way through to the end of life stage and bereavement.
- are supported to stay physically and mentally well and have access to psychological therapies.
- have regular breaks from their caring role and given the opportunity to pursue interests individual to them as well as accessing or maintaining paid or unpaid work.

- are offered one-to-one support and provided with opportunities to meet other family and friend carers.

## 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."

### Overview

More people in West Sussex are living for longer, many not in good health and spend years living with complex and long-term health and care needs such as dementia. This puts extra demand on health and care services and makes it more difficult for patients to receive the right level of care. There are some risk factors 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 - high blood pressure - lack of exercise - obesity - poor physical health - smoking.

Other risk factors that could contribute to the risks are: hearing loss, depression and social isolation.

The are many services, groups and activities working to help reduce the risk factors associated with dementia but there needs to be a whole systems approach to this. A whole system approach works with communities and stakeholders to both understand the problem and to support identification and testing of solutions.

For many people, there is a lack of understanding about the risks of dementia and this is particularly so for people with learning disabilities or those from Black and Minority Ethnic (BAME) groups who are at an increased risk.  Greater awareness raising needs to take place about the modifiable risks through communications, community events, health checks etc.

### Preventing Well - Key Issues & Challenges

- Communicating good quality information about risk factors, early signs of dementia and the benefits of diagnosis across the population but particularly for people from hard to reach groups including black and minority ethnic (BAME) communities where there is an increased risk of dementia and the diagnosis rate has been historically low.
- Risk factors that may contribute to dementia across the life course such as educational attainment, physical inactivity etc. as identified in the Joint Health & Wellbeing Strategy.
- For people with learning disabilities, particularly Down's Syndrome, where there is an increased risk of dementia, there is a need to ensure that they

and their families and carers have access to information, in an accessible format, at an early stage about the risks of dementia and the early signs.

- Family and friend carers are at increased risk of loneliness and physical and mental health problems.

**Prioritising prevention**

The recent government policy document 'Prevention is better than cure' (2018) sets out a call to action for prevention to be at the heart of everything we do. This is reiterated by the NHS Long Term Plan (2019) positive shift towards prevention and reducing health inequalities. The Plan also emphasises the need to make better use of Digital Technology.

| Our Goals | What we mean |
|---|---|
| People live, work and play in environments that promote health and wellbeing and support them to live healthy lives. | • Reduction in people who are overweight or obese.<br>• People are aware of the impact that their alcohol consumption and smoking is having on their long-term health.<br>• People are more physically active.<br>• People with learning disabilities receive regular Annual Health Checks.<br>• Greater awareness of the preventable risks of dementia across the life course i.e. younger people and people in mid life.<br>• Good access to green spaces, leisure centres etc. |
| Individuals, families, friends and communities are connected. | • To work with our communities and partners to empower and support networks of families, friends and communities to find solutions to local problems which have an impact on dementia risk. (West Sussex Joint Health & Wellbeing strategy 2019-24) |
| There is greater awareness and understanding of the factors that increase the risk of dementia and how people can reduce their risk by living a healthier life | • For people to have access to information and advice so that they understand the risk factors for dementia and how their risk could be reduced.<br>• Greater awareness of the risk factors of dementia across the life course such as educational attainment, physical inactivity etc. as identified in the Joint Health & Wellbeing Strategy.<br>• Carers are supported to remain physically and mentally well (West Sussex Joint Commitment to Carers 2015-20)<br>• There is greater public awareness about dementia and increased understanding to reduce stigma. |

| Our Goals | What we mean |
|---|---|
| | • All groups of people including those from black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities as well as people with learning disabilities are aware of the symptoms of dementia and know what steps they can take to reduce their risks.<br>• People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can also be reduced.<br>• Adults aged 40 to 74 access the free NHS Health Check that is designed to spot early signs of heart disease, diabetes, kidney disease, stroke and dementia. An NHS Health Check also help find ways to lower the risk and provides information on dementia risk reduction. |
| Early intervention and ongoing support for hearing and sight loss | • Given the evidence of a link between hearing loss, cognitive decline and dementia, early intervention and on-going support for any underlying hearing loss may have an important role to play in reducing both the risk and impact of dementia. National Institute for Health & Care Excellent (NICE) recommends that local services consider: referring adults with diagnosed or suspected dementia or mild cognitive impairment to an audiology service for a hearing assessment and referring adults with diagnosed dementia or mild cognitive impairment to an audiology service for a hearing assessment every 2 years if they have not previously been diagnosed with hearing loss.<br>• There should be greater awareness of the need to receive regular sight tests and hearing tests. |

**Preventing Well - Examples of Local Key Initiatives (commissioned and non-commissioned)**

- Social prescribing service being run out of a number of West Sussex GP surgeries. Social prescribing involves empowering individuals to improve their health and wellbeing and social welfare by connecting them to non-medical and community support services.
- West Sussex Wellbeing hubs coordinate services that can help improve a person's health and wellbeing. There are local teams that can give advice and support on how to make small changes to improve health and wellbeing, such as how to stop smoking, how to become more active or how to make

meals healthier. Wellbeing is a friendly and impartial service. Most of the services are free or at very low cost.

- NHS Health Check is a national programme in England for people between the ages of 40 and 74. It is a free 30-minute check to assess the risk of developing heart disease, stroke, diabetes and kidney disease. An NHS Health Check also helps find ways to lower the risk and provides information on dementia risk reduction.
- Thriving Connections is sponsored by Adur & Worthing Councils, the County Council and the Clinical Commissioning Group. This is a project focusing on ways that loneliness and social isolation might be tackled in a more innovative way.
- Make Every Contact Count (MECC) – an initiative aimed at providing the knowledge and skills to enable public facing workforces to deliver very brief interventions on health and wellbeing.

**Preventing Well - Key Data**

In 2017/18:
948 adults were supported through the Wellbeing Hubs.
948 people attended strength and balance classes
846 people improved physical activity levels
866 people lost weight
68% of adults physically inactive
62% adults classified as overweight or obese
13% of adults were smokers
41% of adult social care service users who have as much social contact as they would like.
35% of adult carers having as much social contact as they would like.

In 2018-19 35.5% of those eligible took up the offer of an NHS Health Check

20–40% of people with dementia will have depression. (reference)[5]
Depression is more common in people with dementia than those without.
Depression is also common among family carers

## DIAGNOSING WELL

"West Sussex County Council and the Clinical Commissioning Group want to see all groups of people diagnosed earlier and get timely access to good quality post-diagnostic support. With a named coordinator and support to plan their future care along with those people important to them."

### Overview

- According to Alzheimer's Society, 1 in 14 people over 65 and 1 in 6 people over 80 is expected to have dementia. A diagnosis of dementia, like many other illnesses, can be traumatic but for many people it can also come as a relief. It can help people to plan-ahead while they are still able to make important decisions and to access follow-up support. Support that can enable they and their family and friends the ability to maximize control over their lives and manage their condition so that they can live independently for longer. For some people a diagnosis of dementia may not be appropriate, or it may not be their wish to have a diagnosis.

- In West Sussex, the pathway to diagnosis is normally through the GP who will refer the patient to the Dementia Assessment Service (DAS) once all other reversible causes of cognitive decline are ruled out. DAS was formerly known as the Memory Assessment Service (MAS). The DAS provides a high-quality diagnosis and follow up support for the patient and their family and friend carer from a Dementia Adviser.

- There can often be a long wait to diagnosis which can prove to be a very stressful time for the individual and their families and carers. It is therefore important they are offered access to support during this very anxious time. There is a universal offer of information, advice and support from Carers Support West Sussex and robust mechanisms should be put in place to ensure carers awaiting a diagnosis have access to this support.

- Information and advice are key to ensuring the individual and their families and carers can live well with the condition. Once people have received a diagnosis of dementia, they should be provided with the right level of information and advice in a format that is right for them. There should be a 'no wrong door' approach to how people access information and advice. It should be well coordinated, with all information providers offering an equitable level and quality of information about, for example, living with dementia, welfare benefits and available support.

- The individual along with those people who are important to them need to be given the opportunity to plan for their future care and contingencies at the point of diagnosis. This plan should be reviewed at regular intervals in the person's pathway. Care planning provides an opportunity for people to be able to draw on their own strengths and assets and identify where additional support is required.

The Prime Minister's Challenge on Dementia recommends that a named co-ordinator is appointed who has a good understanding of the person and their needs along with how to navigate the health and social care system. In West Sussex, the GP is the named co-ordinator who is responsible for ensuring that the person receives regular care plan reviews and is linked into local support networks.

- Any information, advice and support following diagnosis should be tailored to include the needs of people under the age of 65, people with alcohol related dementia, people with learning disabilities, black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community.
- The Prime Ministers Challenge also recommends that people diagnosed with dementia and their families and carers should be given information about how they can participate in research after diagnosis and at each stage in their journey.

**Early Onset Dementia**

Younger people with dementia (under the age of 65) face different issues, not least that they are more likely still to be working or have a young family. As this disease has been considered 'rare', there is often a long wait to diagnosis as other conditions are explored. Support designed for older people with dementia is often not suitable. This means that people with early onset dementia can find themselves isolated within the community.

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

For older LGBT+ people, living with dementia can be additionally stressful. Not only is this group of people less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many LGBT+ people fear that mainstream care services will not be willing or are not able to understand how to meet their needs. As a more vocal and open generation follows behind, dementia services need to consider how they will meet the challenge.

**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, one in three of whom will develop dementia in their 50s. However, in West Sussex, the pathway to diagnosis is patchy.

Symptoms of dementia can present differently so that people often do not recognise changes as being dementia related. Because of this, opportunities for early intervention are lost. It is important that people with learning disabilities are offered baseline assessments and regular reviews so that signs of dementia can be picked up at an early stage. It is also important for those people and

organisations supporting them to be aware of the signs of dementia and how to care and support the individual as their dementia progresses.

**Sensory Loss**

It is important that hearing and sight are both checked for and ruled out as a potential dementia before the person is referred for a diagnosis. This can prevent an unnecessary referral to the Memory Assessment Service and anxiety to the individual.

Living with both dementia and sensory loss presents challenges. Dementia can cause problems with vision and hearing, without an eye or ear condition causing it, and this may make it difficult to recognise the loss of hearing or eyesight as it develops. Regular hearing and sight tests, technological aids, environmental improvements, and accessible information and communications can all make a big difference for people with dementia and sensory loss.

**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. There needs to be an emphasis on how we reach people from these communities with information about prevention and identifying the early signs. Services designed to support the person need to be culturally sensitive.

**Alcohol Related Dementia**

Alcohol related dementia is more common in people in their 40s and 50s and comprises about 10% of the cases of young onset dementia diagnosed. The condition is poorly understood and often missed by health professionals. Patients struggle with the 'double stigma' of dementia and alcohol addiction and often end up in accident and emergency units because of a lack of community services or clear pathways to support. They also experience longer stays in hospital (reference).[6]

**Diagnosing Well - Key issues and Challenges**

- The fear of stigma can prevent a person from accessing a diagnosis, there is a need for good information to be available about dementia and the benefits of diagnosis.
- Early signs of dementia not being recognised in people with learning disabilities and baseline assessments not taking place.
- Sensory impairment and other conditions can be confused with dementia. It is important for these to be ruled out before referral to the DAS.
- Long waits to diagnosis leading to people dropping-off the waiting list.

- Lower rates of diagnosis among people from BAME communities and in people with Alcohol Related Dementia.
- At the point of diagnosis, people receive a raft of information and advice, but it is not always easy for them to know where to access information and advice at a later stage.
- A system that is complicated and disjointed where people can get 'lost' along the way particularly when their needs change.
- Care plans not being shared with all those involved in the person's care.
- Services staying connected to the person living with dementia.

| **Our goals** | **What we mean** |
|---|---|
| People recognise the early signs of dementia. They know what steps to take to receive a diagnosis and the benefits of diagnosis. | • Dementia awareness raising through dementia friends training, media communications, social networking.<br>• People and organisations supporting the person suspected of having dementia in different settings such as housing support, residential and nursing care are skilled in identifying the symptoms and know what steps to take to support people to receive a diagnosis. This includes people and organisations supporting people with learning disabilities, younger people and people with alcohol related dementia.<br>• A baseline assessment of the level of functioning for people with learning disabilities should be recorded at an early age so that any reduction in ability can be linked to the possible development of dementia.<br>• For cognitive impairment and all other conditions such as hearing and eye sight to be assessed and ruled out before a referral to the DAS. |
| All groups of people to have access to a timely diagnosis including younger people with alcohol related dementia, people with learning disabilities and people from minority groups. | • For all groups of people suspected of having dementia to have access to a timely quality diagnosis in an appropriate setting within a specified number of weeks. This includes people under the age of 65, people with alcohol related dementia, people with learning disabilities and people from BAME and minority groups such as Gypsy and Travelling Communities.<br>• |

| Our Goals | What we mean |
|---|---|
| | • For people who are deaf or hard of hearing or have a visual impairment are identified, with correct support and where appropriate onward referral to the DAS.<br>• The referral rate for people from BAME groups to reflect the ethnic makeup of that geographic area.<br>• Support is available for the person being assessed and their families throughout the diagnostic process.<br>• For people in care settings showing signs of dementia to receive an alternative diagnosis where the full memory assessment process would not be in the best interests of the individual.<br>• GPs and practice nurses to use long term conditions clinics and health campaigns (e.g.: seasonal flu) to consider whether older people at risk of dementia have symptoms that may require further consideration. |
| Improved access to information and advice | • People diagnosed with dementia and their family or friend carers have easy access to information on planning and making choices about their care at the end of life. Information and advice should be joined up and easily accessible throughout the person's journey and as their needs change.<br>• Information and advice providers should offer a 'no wrong door' approach to the level and quality of the information they provide. |
| Improved access to good quality joined up support before and after diagnosis | • People awaiting a diagnosis along with their family and friend carers have access to joined up support whilst they await their diagnosis. There should be a robust referral route to providers that will provide support without a formal diagnosis of dementia such as Carers Support West Sussex.<br>• People receiving a diagnosis of dementia from the DAS together with their family or friend carers receive an offer of support following their diagnosis. This should include an extensive group programme.<br>• Family carers should be given the opportunity to speak openly about the diagnosis their loved one has received either with them or separately. |

| Our Goals | What we mean |
| --- | --- |
| | • Post-diagnosis support to be tailored to include the needs of people under the age of 65, people with alcohol related dementia, people with learning disabilities, black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community. |
| People have the opportunity to plan for their future care and contingencies along with those around them | • A care plan is developed together with the person and those involved in their care that is individual to the person's needs. A plan that includes the person's choices, hopes and aspirations which can guide professionals involved in their care. The care plan should consider cultural identity and faith etc.<br>• The care plan should be used across the whole health, social care and community sector to ensure that all organisations understand the needs of the person with dementia, including recognising any additional conditions the person might have and their potential impact. Emergency and contingency planning needs to be embedded within the care and support plan.<br>• Ongoing review of the care plan at least annually or more often if the person's needs and wishes change, by a health or social care professional skilled in care planning.<br>• There is an easy route back into support if required at any point in the person's journey to ensure that those people affected by dementia do not fall through the 'net'.<br>• People with dementia to be given the opportunity to plan for their end of life care and preferences, beliefs and values regarding their future care. This should take place at diagnosis, review or when circumstances change. There should be opportunities for the individual to change any decisions they have made. |

**Diagnosing Well - Examples of Local Key Initiatives (commissioned and non-commissioned)**

Dementia Assessment Service - a one-stop model to streamline dementia diagnosis within secondary care.

DiADeM (the Diagnosis of Advanced Dementia Mandate). DiADeM is a tool to support GPs in diagnosing dementia for people living with advanced dementia.

West Sussex County Council (WSCC) Supporting Lives Connecting People - Prevention focused drop-in sessions alongside pre-booked Talk Locals meetings. Drop-in sessions help people to access local advice, information and services to support them to stay as independent as possible in their local communities.

**Diagnosing Well - Key Data**

In the last 4 years the average percentage of referrals waiting more than 4 weeks for an assessment from the Memory Assessment Service (MAS) was 40% in Coastal, 66% in Crawley and 57% in Horsham and Mid Sussex 57%.

In 2014 the diagnosis rate for West Sussex stood at 46%, in November 2019 it was 66.1%. A rise of over 20%!

In 2018/19 the MAS made 1,525 diagnoses of dementia. 39% through Chichester and Bognor MAS, 26% through MAS South and 35% through North West Sussex MAS.

In West Sussex, there are approximately 2000 people over the age of 65 from non-White British communities with an estimated 298 people living with dementia*. However, only 3% of people diagnosed through the MAS in 2018/19 were non-White British, i.e. 46 people.

*Based on Alzheimer's Society data - 1 in 14 people over 65 and 1 in 6 people over 80 is expected to have dementia.

**Table 7**

**Diagnoses of Dementia through Memory Assessment Service**

| | **2014/15** | **2015/16** | **2016/17** | **2017/18** | **2018/19** | **%age change (median) over time** |
|---|---|---|---|---|---|---|
| **Total referrals** | 3488 | 3624 | 3641 | 3572 | 3921 | 4% increase |
| **No. diagnoses of dementia** | 1322 | 1460 | 1382 | 1409 | 1525 | 5% increase |
| **%age of diagnoses of dementia to referrals** | 38% | 40% | 38% | 39% | 39% | NA |

**Diagnosing Well Key Data continued**

In 2018/19:

1251 people with dementia and 990 family and friend carers accessed post diagnostic interventions provided through MAS.

There were 1233 referrals into the Dementia Adviser service.

4004 people accessed information and advice commissioned through Public Health social support services.

## 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."

### Overview

- The person with dementia and their family and friend carer need to be put at the centre of their care. It is essential they know how to access information and support as their dementia progresses and have opportunities to plan ahead for their future care while they are still able to do so.
- For many people dementia is not the only long-term condition they live with and they need to be enabled to manage the dementia and other conditions as much as possible for themselves. This requires a joined-up pathway of support, including between primary, community and hospital provision. The valuable contribution provided by voluntary and community sector providers as well as many smaller community-led providers is also essential and needs to be included in the pathway of support. People should not have to re-tell their story every time they encounter a new service and providers need to ensure that information (such as care and support plans and advance care and support plans) can be easily transferred between different care settings.
- 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. People with dementia and their families need to be confident that, when a need arises, they can receive the support they need without having to make multiple approaches. West Sussex County Council (WSCC) Adults Services, Proactive Care and Specialist Dementia Care Services work together to provide a joined-up offer of support. Care is coordinated and there is less of an emphasis on reactive crisis intervention and unplanned care/hospital towards independent health and wellbeing. Services work with the individual to enable them to see the value they themselves bring and the resources around them.
- People with dementia need to live in suitable housing that meets their changing needs and there needs to be information and advice about housing provided at the point of diagnosis.
- Local house planning needs to reflect the growing need and the rise in prevalence across the county. Housing providers can also play a key role by supporting Dementia Friendly Communities and ensuring their staff are dementia aware. They can help identify the symptoms of dementia and encourage people to seek support.

- For many people with memory loss, living at home can be challenging and often just a small intervention such as a personal alarm can help the person to be able to remain at home for longer and provide peace of mind for their families and carers. There needs to be a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence. Technology enabled care services (TECS), that is technologies such as telecare and telehealth, and self-care apps can help people to manage and control chronic illness and maintain their independence.
- Extra Care Housing can be an attractive option for someone living with dementia as it offers the security of having care staff on hand but without losing the independence of living in your own home. In West Sussex, there are 13 Extra Care schemes that the County Council nominate customers to, of these 12 schemes have commissioned care contracts through the Council.
- As the condition progresses, it may become necessary for the person with dementia to require some additional care and support to enable them to live at home safely. It is recognised that good quality domiciliary care and access to community-based opportunities for active engagement can contribute to maintaining a person's independence, reduce social isolation, prevent admission and/or delay the permanent admission to care homes and/or hospital. The Council continues to actively engage and support the market development of care and support at home providers to ensure excellent delivery for people accessing these services.
- For those people whose needs have increased to the point they are unable to live at home, a residential or nursing care home setting may be more appropriate. 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 including how it will be funded. In West Sussex, the largest number of specialist dementia care homes are located in the Coastal area (55%) with only 5% and 9% in Crawley and Horsham respectively. As a local authority West Sussex County Council (WSCC) has a responsibility for quality of provision, market shaping and sufficiency of supply in its local area, however this is reliant on working with other partners including local planners, health, care providers and on staffing.
- For people with dementia there is a greater risk of an unnecessary hospital admission, together with longer stays and delays to discharge. A national Care Quality Commission (CQC) thematic review showed that in most NHS acute trusts, people with dementia stayed significantly longer and were more likely to be readmitted or die in hospital. Wherever possible, admissions to hospital for people with dementia should be avoided and where this is not possible, stays should be as short as possible. Services need to work together to provide a joined-up approach to supporting the person at risk of an unplanned hospital admission or delayed discharge.

- Hospitals can be disorientating and confusing places for someone with dementia and there can be issues with eating, drinking and pain relief during their stay. Sensitivity, compassion and empathy are core qualities that doctors, nurses and all hospital staff should have for their patients, as are listening and communicating. Hospitals should provide dementia friendly environments.
- All hospital staff should be skilled in dementia care at a level appropriate to them. West Sussex hospitals have robust dementia training programmes in place that are targeted at all levels of staff. Family and friend carers are key to the wellbeing of the person with dementia whilst the person is in hospital and they also need support at this difficult time.
- For carers, a stay in hospital either for them or the person they are caring for can be particularly stressful. Carers Support West Sussex has teams working within hospitals offering support with discharge planning and information and advice. Additionally, John's Campaign, a movement to help NHS staff recognise the importance of working with family carers as equal partners in the care and support of people with a dementia, is being used by hospitals in West Sussex.
- In West Sussex, services such as Home from Hospital, Take Home & Settle and Relative Support ensure the patient and their family and friend carer are supported to return home safe and well.

**Supporting Well - Key issues and challenges**

- There is a lack of clarity about eligibility for dementia services.
- The All-Party Parliamentary group (APPG) report from 2016 suggested almost 7 in 10 people with dementia also have one or more other health conditions. However, services often work independently of each other and there is little joined up working.
- Services designed to keep people at home are stretched and struggle to meet demand.
- People with dementia from the LGBT+ community can feel that services are not able to understand how to meet their needs.
- Crises are common in people with dementia and can lead to unplanned admissions to hospital and residential care, but services designed at keeping people at home are stretched and struggle to meet demand.
- Lack of 24/7 crisis support.
- Falls and fractures are a particular issue for people with dementia and can lead to hospital admission and loss of independence. Lower-body strength exercises and balance exercises can help prevent falls and avoid the disability that may result from falling.

- People with dementia often experience longer stays in hospital, delays in leaving hospital and reduced levels of independent functioning. (reference)[7]
- Delays in discharging people with dementia safely from hospital because of issues such as finding placements and packages of care for people living in rural communities or for people with complex and challenging needs; together with delays in social care assessments and funding decisions.
- Sufficient capacity within the care market and recruitment of care staff to meet the needs of people with dementia requiring long term residential and nursing care or short-term respite. Particular issues for people with more challenging needs and people with Early Onset Dementia.
- Over stretched resources including staff and time.
- Gaps in staff training and often lack of confidence in supporting someone with complex and challenging needs.

| **Our goals** | **What we mean** |
|---|---|
| For people to be enabled to live independently at home | • People have easy access to adaptations to the home and technology that allows them to live at home safely. For example, ramps, grab rails, movement sensors, personal alarms, trackers.<br>• People with dementia live in housing that meets their needs and house planning reflects the needs of people with dementia.<br>• Housing providers are skilled in dementia awareness.<br>• The risk of falls is caused through physical inactivity, poor hydration and nutrition, sensory impairment and home hazards are prevented.<br>• There is a co-ordinated offer of information, advice and guidance that enable people to have choice and control over their health and independence.<br>• There is sufficient local provision of care and support at home where more support is required. For services to be flexible in how they support the person living with dementia and help people to help themselves more through focussing on outcomes rather than processes.<br>• People with hearing or sight loss have access to regular hearing and sight tests, technological aids, environmental improvements, and accessible information and communications. |

| Our Goals | What we mean |
| --- | --- |
| To reduce the risk of loneliness and social isolation for people with dementia living alone. | Active and inclusive communities, which support people to develop and maintain connections to friends and family.<br>• People have easy access to adaptations to the home and technology that allows them to live at home safely. For example, ramps, grab rails, movement sensors, personal alarms, trackers.<br>• Access to welcoming and inclusive public or community transport that enables people with dementia who are no longer able to drive the ability to participate in a wide range of activities. |
| For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia | • The person with dementia and those around them need to be put at the centre of their care.<br>• Dementia needs to be seen as a long-term condition that requires on-going management over a period of years. Inevitably it is very common for people with dementia to also have other long-term conditions. Therefore, it is essential that people with dementia, their families and carers know how to access support as their dementia or other health conditions progress. This requires an integrated pathway of support, including between community and hospital provision.<br>• People should not have to re-tell their story every time they encounter a new service, and to not get the support they need because different parts of the system do not 'talk' to each other or share appropriate information and notes.<br>• Service providers to ensure that information (such as care and support plans and advance care and support plans) can be easily transferred between different care settings (for example home, inpatient, community and residential care).<br>• Patients should experience a smooth and timely transition from hospital back to their home environment. Hospital and community teams need to work together from admission, to tackle factors that could prevent a safe and timely transfer of care from hospital and to ensure the patient and their family and friend carer, is at the heart of any discharge planning. |

| Our Goals | What we mean |
| --- | --- |
| Approaches to care and support that are individual to the person's needs and for the person to be enabled to self-manage their dementia and other conditions | • Support is built around the individual with dementia, their carer and family and provide them with more choice, control and flexibility in the way they receive care and support – regardless of the setting in which they receive it.<br>• The individual and their family and friend carers are enabled to see the value they themselves bring and the resources around them.<br>• Care and support are delivered in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities.<br>• Ease of access to information and advice and advocacy services where there is not an appropriate person to represent the individual.<br>• Life Story work is an activity in which the person with dementia is supported by staff and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with past events.<br>• People with dementia should be given the opportunity to express their own views and opinions about their care in a format that is appropriate to them i.e. through visual aids, simplified text etc.<br>• People with dementia are enabled to manage their dementia and other long-term conditions themselves. |

| Our Goals | What we mean |
| --- | --- |
| Compassionate care and support from staff skilled in dementia | • Education, training and development opportunities available for those people and organisations providing care and support for people with dementia at a level that fits with their individual responsibilities. Education and training should focus on:<br>  ○ identifying symptoms of dementia and know what steps to take to support people to receive a diagnosis.<br>  ○ acquiring greater awareness and understanding of dementia, so that they can help to ensure people are diagnosed and supported earlier.<br>  ○ becoming better equipped to help people in crisis to remain at home or return home after a hospital admission.<br>  ○ having awareness of the impact of dementia on the person living with the condition and their families.<br>  ○ Getting to know the person, their history and interests, and understand how dementia is affecting their life in order to be able to offer care and support that is individual to them.<br>  ○ Giving consideration to the person's individual characteristics including age, disability, gender reassignment, marriage and civil partnership status, race, religion and belief, sex and sexual orientation.<br>  ○ Starting and holding difficult emotionally challenging conversations such as end of life care planning.<br>• For there to be a framework for dementia training to ensure all people receive training relevant to their role so that there is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia and is equipped to do so.<br>• The Framework for Enhanced Health in Care Homes (EHCH) is based on a suite of evidence-based interventions, which are designed to be delivered within and around a care home in a coordinated manner.<br>• All healthcare assistants and social care support workers to have undergone training as part of the national Care Certificate. Staff competency and accreditation in dementia care skills should be regularly monitored and reviewed. |

| Our Goals | What we mean |
|---|---|
| | • Workers supporting people with learning disabilities and dementia to be skilled in supporting someone to remain in their normal care setting for longer following their diagnosis. When this is no longer possible, and the person needs to move into a dementia specialist facility, care workers should be trained in supporting the person with both their dementia and learning disability needs. |
| Dementia and carer friendly health and care settings | • If thought is not given to the way that a person with dementia interacts with their environment, this can result in increased agitation and behaviours that challenge, falls, confusion and can hinder the delivery of person-centred care. A dementia-friendly environment is one where buildings and physical environments do not prevent people with dementia from accessing them.<br>• The role the family and friend carer plays in the care of the person with dementia cannot be under-estimated and in all care settings they should be: identified and supported and recognised as partners in their loved one's care. |
| For support to be in place to avoid wherever possible unplanned admissions to hospital or inpatient facilities.<br><br>Where hospital admissions are required, for these to be as short as possible. | • Wherever possible, admission to hospital and inpatient facilities should be avoided by a community crisis response and social care support for both the person with dementia and their family and friend carer. Where home treatment is not possible, patients should receive compassionate care by skilled staff, in dementia and carer friendly environments.<br>• The person living with dementia along with their family and friend carer should be supported to develop a contingency plan as early on in their journey as practical.<br>• For only the most complex patients to need admission to an inpatient bed. Where admission is needed, the stay will be as short as possible with integrated discharge support to ensure that discharge home or to care/nursing home is not delayed. |

| Our goals | What we mean |
|---|---|
| The risk of a crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support | • Early conversations should take place the person living with dementia and their family and friend carer so that they can plan ahead for their future care while they are still able to do so.<br>• Wherever possible, admission to hospital, inpatient facilities or residential care should be avoided by a community crisis response and social care support for both the person with dementia and their family and friend carer.<br>• The following contributory factors to a crisis should be identified and interventions provided where necessary:-<br>o Family and friend carers unable to cope with their caring role.<br>o The person with dementia presenting behavioural and psychological characteristics.<br>o Physical health problems.<br>o Social factors related to the person with dementia or their environment. |
| People with dementia and their families have a good experience of support provided by Care Homes and that there is sufficiency of quality, affordable provision within West Sussex that reflects the needs of diverse communities. | • Staff in all care homes to be able to identify the symptoms of dementia and know how to access support.<br>• Care staff know what to do to avoid an unnecessary hospital admission.<br>• There should be mechanisms in place for supporting excellent dementia service leadership.<br>• The family and friend carer should be considered partners in the care of the resident.<br>• There should be a diverse provider market that can deliver culturally sensitive support and support for people from the LGBT+ community.<br>• Care homes should develop good links into their communities and become part of their local dementia friendly community. |

**Supporting Well - Examples of Local Key Initiatives (commissioned and non-commissioned)**

- The Council's Dementia Learning Framework on the Learning & Development Gateway provides easy access to learning about dementia for all people and organisations supporting someone with dementia.
- Support for people with dementia and long term health conditions across Coastal West Sussex from the Community Proactive Care Plus teams.

- Time for Dementia programme provides undergraduate healthcare professionals with on-going, regular contact with a person with dementia and their carer.
- Dementia friendly Hospital Charter being rolled out by Western Sussex Hospitals Trust.
- 'This is About Me' and 'Knowing Me' tools to provide key information for hospital staff about their patients.
- 'Connect with dementia' – a volunteer service being run at Crawley Hospital and Zachary Merton in Rustington
- An in-hospital Carer Wellbeing Service for family and friend carers through Carers Support West Sussex.
- Home First – Discharge to Assess model. A service that enables people to be effectively and efficiently discharged from hospital.
- 'Hospital to Home' clinic at Horsham Hospital for providers to come and share information with patients.
- Dementia champions across Intermediate Care Units and considerable investment to improve environments to make them more dementia friendly.
- New Dementia In-patient facility that is a Centre of Excellence in Worthing for people living with dementia which will improve the care for both their mental and physical health needs.
- Re-focus of Council's in-house services on delivering support which makes the most of people's wellbeing and independence such as day services, residential care homes and 'Shared Lives' scheme.
- Care & Business Support Service - A Council initiative that provides professional support to local services in the care sector.
- Proud to Care – An initiative run in collaboration with the Council and NHS that works proactively to support the nursing and care sector to develop recruitment, retention and capacity plans and to identify and support providers with workforce training.
- PatchCare® from Caremark - an innovative approach to home care, delivering a wide range of personalised care services. It covers small geographical patches. Clients benefit from regular, more tailored visits throughout the day.

**Supporting Well - Key Data**

In 2018/19 5,327 people used the Home from Hospital, Take Home & Settle and Relative Support services.

There are approximately 132 residential and nursing homes in West Sussex specialising in dementia – offering 5104 beds.

In 2017/18 there were 2761 per 100,000 emergency admissions to hospital in West Sussex for people with dementia* 848 less than nationally. (*Dementia: Direct standardized rate of Emergency Admissions (aged over 65) (reference)[8]

There are around 65 referrals each month into the Dementia Support Service with 80% coming from family carers.

In 2017/18 Carers Support West Sussex received 1293 referrals for equipment for independence.

There are around 13 Extra Care Housing schemes commissioned by the County Council.

There was 5,100 referrals to the Hospital Carer Wellbeing service in 2017/18.

**Dementia Crisis Service 2018/19**

| | |
|---|---|
| No. of referrals | 821 |
| Admissions avoided to acute beds | 270 |
| Admissions avoided to mental health wards | 1145 |
| Admissions avoided to care homes | 380 |

**Percentage of Dementia Specialist Care Homes in West Sussex @ 2018/19**

| | |
|---|---|
| Coastal | 55% |
| Chichester area | 17% |
| Crawley | 5% |
| Horsham | 9% |
| Mid Sussex | 13% |

## 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.

**Overview**

- There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community.

  Breaking down the stigma of dementia is key and initiatives such as 'Dementia Friendly Communities' can help people to access their local communities and reduce the risk of social isolation and loneliness. People with dementia have described a dementia friendly community as one that enables them to:

  - Find their way around and be safe
  - Access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices)
  - Maintain their social networks so they continue to feel they belong.

  Local Dementia Friendly Community Groups focus on changing public attitudes through the creation of dementia friendly communities so that people affected by dementia have the best possible opportunities to live well. Dementia Friendly Communities in West Sussex have been growing steadily since the start of the last Dementia Strategy. There is now a Local Dementia Friendly Community Group in almost every major town in West Sussex with almost 300 members. Members include local businesses, community groups, faith groups, schools and colleges, libraries, museums, shopping centres and charities as well as health and social care providers. Local Groups are led in the main by volunteers and without the right support to build capacity this work is unsustainable and over time there will be an impact on how far dementia friendly communities can grow and develop. There needs to be a coordinated response to how Local Dementia Friendly Community Groups are supported and funded.

- Caring for someone with dementia can put a huge strain on the carer's physical and mental health and finances. It can also strain, at times to breaking point, the relationships with other family members. A family and

friend carer needs support so that they can continue in their caring role and enable their loved one to live well with dementia.

Carers should be offered training about dementia, its symptoms, providing care and the changes to expect as the condition progresses. They should be supported to develop a personalised strategy for their caring role. Training should include support with adapting communication styles to improve interaction with the person they are caring for. The carer also needs advice on how to look after their own physical and mental health and their emotional and spiritual wellbeing.

Local Authorities have enhanced duties towards carers since the introduction of the Care Act 2014. In West Sussex, there is a consistent offer of support, information and guidance to all carers delivered by a single provider, Carers Support West Sussex. This provides a gateway service to all other carer support services within the County, such as carer break services and more specialist services.

- People living with dementia need to have access to a range of activities that promote their wellbeing. They should be affordable, easy to get to and tailored to the person's individual needs. Activities should reflect the changing needs of the person with dementia as their dementia progresses.
- Accessing groups and other activities can be particularly challenging for people who may no longer be able to drive, particularly those living in more rural communities and there needs to be a robust plan for ensuring better transport links and provision that is closer to home.
- There needs to be a community-led support approach to how we meet the challenges faced by people affected by dementia. Community-led support focuses on reaching people at an early stage to help prevent or delay the development of their care and support needs and to enable them to be as independent as possible. Supporting Lives, Connecting People is the name used for delivering community-led support to adults in West Sussex. Sessions known as Talk Locals are held in local communities where people can speak face-to-face with staff from a range of disciplines about their situation and find suitable solutions on the day of the appointment if possible.
- The Council, Clinical Commissioning Group, voluntary and community sector organisations, including smaller providers, deliver a diverse set of services to enable the individual and family and friend carer to live well. These can include daytime activities and short break respite opportunities that provide a much-needed break for the carer from their caring role. Services are delivered either in the person's own home on a one to one basis, or through group activities away from home this can include: day services; outings and dementia cafes. There are also services in place to provide short term support for someone in their own home including emergency respite for the family carer and support for people to settle back at home after a stay in hospital.

- Access to information and advice about living with dementia, welfare benefits and the support available is key to ensuring all people affected by dementia can continue to live well with the condition. Information about services that can support the person and their families and carers should be easily accessible and provided in a co-ordinated way. Information and advice providers should offer a 'no wrong door' approach to the level and quality of the information they provide. In West Sussex, there is a universal offer of information and advice for people with dementia and family and friend carers from Alzheimer's Society's Dementia Support Service and Carers Support West Sussex along with a county-wide information and advice service commissioned by Public Health. In addition, a dementia zone on the West Sussex Connect to Support website provides information about dementia and local services and support.

**Living Well - Key issues and challenges**

- Family and friend carers can become cut off from the community leading to social isolation and resultant worsening of health. They need easy access to peer support, carers groups and other initiatives that help them to stay connected.
- Lack of flexible breaks for carers impacting on the carers ability to continue effectively in their caring role.
- Historically low uptake to services from people with dementia from Black and Minority Ethnic and seldom heard groups.
- People from LGBT+ communities having opportunities to participate in services designed to support them to live well.
- For people with Early Onset Dementia to have support to engage in age appropriate activities.
- Sustainable Dementia Friendly Communities - Local Dementia Friendly Community Groups rely mainly on volunteers and on short term time limited financial support which impacts on the sustainability of this work.
- Transport can be a particular challenge particularly for someone living in more rural communities and/or where they can no longer drive.
- More local activities needed for people with dementia and their family and friend carers to participate in.
- Support for people with dementia to take part in non-specialist/mainstream groups and activities.

| Our goals | What we mean |
| --- | --- |
| People have access to a range of affordable flexible activities that reflects their interests and needs and are appropriate to their age and the stage of their dementia | • Dementia specific services or support to access non specialist/mainstream activities to be designed to meet the needs of all people including those who:<br>  ○ do not have a family or friend carer<br>  ○ do not have access to affordable transport, or find transport difficult to use;<br>  ○ have sensory impairment or physical difficulties;<br>  ○ are less likely to access health and social care services such as people from the LGBT+ community, Gypsies and Travellers and black, Asian and minority ethnic groups.<br><br>• Activities thought to benefit the person with dementia include: Physical based activity, Outdoor activity, Reminiscence based, Arts based activities, Music based activities. (A recent systematic review for the What Works Centre for Wellbeing concluded that there was evidence of wellbeing benefits of singing among people with dementia.)<br>• Age appropriate activities or support to access non specialist/mainstream activities for people with Early Onset Dementia and Alcohol Related Dementia.<br>• Activities are available that are appropriate to the person with dementia as their dementia progresses. |
| There is a whole community response to living well with dementia in safe and enabling communities | • Dementia friendly communities grow stronger and become sustainable.<br>• There is a coordinated response to how Local Dementia Friendly Community Groups are supported and funded.<br>• All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and action plans. |

| Our goals | What we mean |
| --- | --- |
| | • The roll-out of dementia friends sessions to enable people to learn what it is like to live with dementia. A Dementia Friend learns what it is like to live with dementia and then turns that understanding into action – for example, by giving time to a local service such as a dementia café or by raising awareness among colleagues, friends and family about the condition.<br>• All employers with formal induction programmes to include dementia awareness training within these programmes.<br>• For younger people to be more educated and aware about dementia.<br>• Public sector organisations taking a leadership role by becoming dementia friendly organisations.<br>• Environments and physical settings in the community becoming dementia friendly places with people living with dementia being able to take advantage of open spaces and nature.<br>• There is a proactive approach from services such as Fire, Police and Trading Standards that supports people living with dementia to live safely in their communities.<br>• Welcoming and inclusive public or community transport that enables people with dementia to be able to participate in a wide range of activities. |
| People can maintain and develop their relationships and be able to contribute to their community | • For people affected by dementia to be enabled to maintain and develop social connections through peer support, carers groups and similar initiatives to help build resilience.<br>• Social action solutions such as peer support and befriending services can also provide practical and emotional support to people with dementia and carers, reduce isolation and prevent crisis. |

| Our goals | What we mean |
| --- | --- |
| | • For family members including dependent children of people with Early Onset Dementia to receive practical and emotional support.<br>• For people with dementia and family and friend carers to be supported to take part in paid and unpaid work. |
| Carers of people with dementia are able to access information, support and training as needed and feel able to continue with their caring role | • For people with dementia and their family and friend carers to be put at the centre of their care and have access to flexible support that is responsive to their personal interests and needs.<br><br>For family and friend carers to:<br>• be identified by all those involved in the care and support of the person they care for and treated as partners in their care.<br>• be offered an assessment of their own needs that considers their emotional, physical and social care needs.<br>• have access to psychological therapies.<br>• have access to advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing<br>• access advice on planning for the future.<br>• have easy access to information and advice in an accessible format at every stage in their journey from pre-diagnosis through to end of life and bereavement.<br>• have access to education and advice in a format that is suitable to them, about the most common problems they are likely to meet, its symptoms and the changes to expect as the condition progresses. For the family and friend carer to have support to build their skills and develop an individual strategy for supporting the person they care for.<br>• have an opportunity to access one-to-one support and peer support in a format that is suitable for them, so as to be able to link up with carers in a similar situation. |

| Our goals | What we mean |
| --- | --- |
| | • be able to access support at a location they can get to easily.<br>• have the offer of regular vital breaks from caring. This can be for a few hours, a day or a week, perhaps longer. It may be provided at home or elsewhere. It could be a regular, planned arrangement, or it may be more occasional. This should include emergency respite if necessary.<br>• have the opportunity to pursue interests that are individual to them as well accessing or maintaining paid or unpaid work. |

**Living Well - Examples of Local Key Initiatives (commissioned and non-commssioned)**

- Training for family and friend Carers such as Carer Information and Support Programme (CrISP) run through Alzheimer's Society and 'Understanding Dementia workshops run through Carers Support West Sussex.
- New Tyne Resource Centre in Worthing offer long stay residential placements, respite and day service for people over the age of 40 who have a diagnosis of dementia.
- The Council's in-house Shared Lives service for people with dementia.
- Dementia Friends training being delivered by Dementia Champions throughout West Sussex and accessed on-line.
- Admiral Nurses - supporting family carers of people with dementia in the community in the north of the County.
- Jointly commissioned county-wide Short Breaks service for family and friend carers through prime providers - Age UK West Sussex, Independent Lives, Carers Trust East Midlands, Age UK Horsham District and Guild Care.
- Specialist support for people with Early Onset Dementia that includes an overnight residential Break twice a year, Neil's Club in East Grinstead, Cando@K2 in Crawley and Centre Club in Worthing.
- Dementia Support at Sage House in Tangmere, offering a Wayfinding service to help guide families through their personal dementia journeys, as well as day care, a range of activities for those living with dementia and their carers, therapy rooms, a salon, a smart zone, and a café.
- Countywide activities to stimulate cognition and provide social interaction such as: Sporting Memories, Dance Well and Thrive, gardening clubs, community sheds.

- Herbert Protocol rolled out by Police Service. For carers to compile useful information about the person they care for that can be used in the event of a vulnerable person going missing.
- Safe and Well visits - a free service carried out by West Sussex Fire & Rescue Service.
- Carers Support West Sussex Dementia Wellbeing programme offering practical support and information to carers.
- Library service offering Memory Management Tickets, Books on prescription, Digital Library Plus Home Visits, Reminiscence collections, drop-ins and Melody for the Mind groups.
- West Sussex Mind helping people over 65 in Bognor and Chichester and Midhurst who are feeling low, have depression, anxiety or other mental health problem, or are simply feeling isolated.

**Living Well - Key Data**

The Council commission Older People's Specialist day services at Glebelands, The Laurels, The Rowans, Chestnuts and Judith Adams.

There are 10 Local Dementia Friendly Community Groups in Arun, Burgess Hill, Chichester, Crawley, East Grinstead, Haywards Heath, Horsham District, Worthing, Selsey and Adur with a membership of around 300.

In 2019/20, there were 32,540 Dementia Friends in West Sussex and 127 champions.

In 2018/19 2540 people accessed Day Activities commissioned by Public Health.

Alzheimer's Society host 5 service user review panels.

According to Alzheimer's Research UK, 32% of carers have as much social contact as they would like. 63.5% say they have had none or not enough support.

In West Sussex, there is a Short Breaks service offering carers a break from their caring role in Adur, Arun, Chichester, Crawley, Horsham, Mid Sussex and Worthing.

Carers Support West Sussex have more than 25,000 registered carers with around 20% identifying themselves as caring for someone with dementia. (2018/19 data)

According to Alzheimer's Research UK, 63% of carers for people with dementia are retired while 18% are in paid work. 15% of dementia carers say they are not in work because of their caring responsibilities.

In 2018/19 almost 200 carers of people with dementia accessed the Carers Health & Wellbeing Fund and were granted more than £53,000 to help them in their caring role.

## 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."

**Overview**

- Research shows that people are more likely to die in the place of their choice if their wishes are known and documented in advance. The government has said that all people with a diagnosis of dementia should be given the opportunity to plan in advance for their care early on to ensure the person and their carer are fully involved in decisions on care at end of life. Open communication that involves the individual and families in decisions, and is responsive to their needs is vital and can vastly improve their experiences.

  It is important to have early conversations with people with dementia and their carers so that they can plan ahead for their future care while they are still able to do so. This reduces the likelihood that difficult and emotional decisions have to be made in crisis, when the wishes of the person with dementia cannot be taken into account.

  Assessment and management of distressing symptoms at the end of life can be greatly helped by a detailed knowledge of the individuals' prior wishes. These type of conversations can often be difficult and it is important that staff involved in these have the necessary training to feel confident about starting the conversation with sensitivity.

  Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision-making is crucial to ensuring that the wishes of the individual living with dementia are reflected in the actions taken. This approach is also helpful for the person's family as they will be directed to services that can support them once their loved one has passed away, such as bereavement services, as well as the formalities that will need to be carried out.

  In West Sussex, the CCGs along with, Sussex Community NHS Trust, Sussex Partnership NHS Foundation Trust, Western Sussex Hospitals Trust and local hospices and services have endorsed an Advance Care Plan 'Planning Future Care' to help identify people's wishes and preferences for their future care. This is being implemented across West Sussex, in the community, care homes, and virtual wards.

- People nearing the end of their life need to receive coordinated, compassionate care that is individual to their needs. This includes palliative care for the person with dementia and bereavement support for carers. Care needs to be delivered by skilled, trained and compassionate staff throughout

the person's life journey. Hospices can play an important role in supporting staff to care for people with dementia, as well as caring directly for people with dementia especially where the person has more than one long term condition. In West Sussex, local hospices and specialist palliative care providers are commissioned to provide end of life training. The training includes specific programmes for care homes. The CCG also supports an education package for NHS End of Life Care Champions.

- The End of Life Care Hub in Coastal West Sussex (ECHO) helps to improve identification of people in the last year of their life; share care plans between services; and provide a more responsive, proactive and person-centred offer of care. The ECHO hub maintains a register of people in their last year of life accessible for clinicians; it provides patient and carer support through a website and 24-hour telephone line. It plans for newly identified patients and responds and reacts to patients' changing needs by co-ordinating access to services.

- It should be recognised that care for one another in times of grief and loss is everyone's responsibility and supportive networks have a key role. The resources in our communities can be harnessed to help improve the experience of the individual. Compassionate Communities is a new initiative from West Sussex that is looking at ways communities can come together to support people during illness, dying and bereavement. In line with National ambitions for palliative and end of life care, they want people in West Sussex to be able to say; "I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

**Dying Well - Key Issues and Challenges**

- Planning future care and end of life support not taking place early enough in the pathway.

- Advance care plans where they exist are not always being shared with all those involved in the person's care.

- Hospital staff caring for people in the last stages of their lives are often unaware of the person's end of life wishes.

- People dying away from their usual place of residence or in a place that is not of their choosing.

- People with dementia may experience problems with thinking, memory, behaviour and mobility. It can be difficult to recognise when someone with dementia is nearing the end of their life.

- Managing pain where there are challenges with communication.

- The need to ensure that families and carers receive the right level of bereavement support and counselling.

| Our goals | What we mean |
|---|---|
| People living with dementia together with their families and carers are enabled to make decisions about their future care | • People living with dementia, their families and carers complete advance care plans as soon after diagnosis as possible and that these are reviewed on a regular basis.<br>• People assessed as not having capacity, with no family or friends are referred to an Independent mental Capacity Advocate as appropriate and supported to plan their care.<br>• The advance care plan to be shared with all those health and social care professionals involved in the individual's care. |
| There is support for people to die with dignity in a place of their choice | • People are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they chose.<br>• People are not admitted to hospital unnecessarily in the last weeks or days of their life nor delayed from being discharged from hospital.<br>• There is a framework for dementia training to ensure all staff receive training relevant to their role.<br>• There is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia in the end stages of life and is equipped to do so. |

| Our goals | What we mean |
| --- | --- |
| People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care | • Care plans and advanced care plans are shared between services in order to provide a more responsive, proactive and person-centred offer of care.<br>• For all those people involved in end of life care, e.g. the GP, district nurses, care staff, speech and language therapists etc to communicate reliably with each other. Without good information-sharing, a person is less likely to receive the care they need. This should extend to ensuring the family understands what is happening and are updated regularly.<br>• Care staff and family and friend carers are equipped with the ability to develop their knowledge, skills and behaviours in order to deliver co-ordinated, compassionate and person-centred end of life care for people with dementia.<br>• People with dementia at the end of their life receive emotional or spiritual support. |
| Families and carers are provided with timely co-ordinated support before death, at the time of death and bereavement | • People in the last year of their life are identified.<br>• Families and carers receive bereavement support at a time that is right for the individual or family.<br>• There is support and signposting available for friends and family going through the grieving process.<br>• There is a recognition within the community that everybody has a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways. |

**Dying Well - Examples of Local Key Initiatives (commissioned and non-commissioned)**

- The End of Life Care Hub for Coastal West Sussex (ECHO).
- The Clinical Commissioning Group's directly commission End of Life education with local hospices and specialist palliative care providers that are open to partners. An education package for NHS End of Life Care Champions has also been supported.
- The Admiral Nurse Service which provides a proactive approach to ensuring family cares receive support and specialist training and education in their caring role particularly at times of crisis and end of life. Admiral Nurses also help with conversations around end of life and transition to residential care.
- Dementia Community Matrons in Adur, Arun and Worthing who support the individual and their families and carers at the end of life.
- End of Life Champions sitting within SPFT Dementia services.
- Public Health currently producing a bereavement pathway.
- Time to Talk – talking therapies services in West Sussex - Bereavement and Reactions to Loss.
- Specialist carer bereavement support through Carers Support West Sussex.
- County-wide WSCC Supporting Lives, Connecting People Talk Local Hubs and Community Drop-in sessions.
- Care homes with Gold Standard Framework accreditation.

**Dying Well Key Data**

In 2017/18 75.5% of people with dementia over 65 in West Sussex died in their Usual Place of Residence.  7% higher than nationally. (reference)[8]

In England and Wales, the number of people living with dementia who need palliative care will almost quadruple by 2040.(reference)[9]

Dementia is now one of the top five underlying causes of death in the UK and one in three people who die after the age of 65 have dementia. (reference)[10]

In the UK, nearly two thirds of people with dementia are women, and dementia is a leading cause of death among women - higher than heart attack or stroke. (reference)[11]

In 2017/18 24% of people aged over 65 in West Sussex died in hospital. 6% lower than nationally.[6]

Echo Evaluation Findings:-

- 83% of Echo patients with a known preference died in their preferred place.
- Only 13.3% of people on the Echo caseload died in hospital.
- Rate of admission to hospital in the last year of life was significantly lower for those referred to Echo than those who were not.
- Average hospital length of stay in the last year of life for Echo patients was lower than for people who were not referred to Echo.

## A JOINT STRATEGIC APPROACH TO DEMENTIA IN WEST SUSSEX

The range of support for people with dementia is fragmented; 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.

A range of partners:-

Family and friend carers, Transport Providers, Dementia Assessment Service, Dementia Advisers, Fire Service, WSCC Adult Social Care, Short Break Providers, Trading Standards, Health Clinics, Police Service, Living Well With Dementia, Dementia Crisis Service, Wellbeing Hubs, Care Providers, Fire Service, Voluntary & Community Providers, Dementia Friends and Champions, Public Health, Carers Support West Sussex, Dementia Friendly Communities, Libraries, Hospices, Primary Care, Admiral Nurses, Hospitals, Local Councils, Proactive Care, Local Dementia Friendly Groups, Primary Care Networks……

## MONITORING DELIVERY AND 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 and 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.

Learning from the first dementia strategy tells us that it is imperative we have systems in place for decision-making and accountability. A Dementia Strategic Partnership Group will be established that will monitor the progress of this Strategy, identify gaps and work together to help find solutions.

# APPENDICES

## Appendix A – Our Guiding Principles

These are based on the 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.

These statements were developed by people with dementia and their carers, and the person with dementia is at the centre of these statements. The "we" used in these statements encompasses people with any type of dementia regardless of age, stage or severity; their carers; families; and everyone else affected by dementia.

These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law and are a rallying call to improve the lives of people with dementia. These Statements recognise that people with dementia should not be treated differently because of their diagnosis.

- Independence/Interdependence/ Dependence - We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- Carers - We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- Community/Isolation - We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- Research - We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.
- Diagnosis and post-diagnostic care and support - We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

## Appendix B – References


[1] Public Health England Guidance – Dementia – Applying all our health 2018

[2] The All-Party Parliamentary group (APPG) report 2016 – 'Dementia rarely travels alone: Living with dementia and other conditions'

[3] Alzheimer's Research UK Dementia Statistics Hub

[4] Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040, CPEC and LSE Raphael Wittenberg, Bo Hu, Luis Barraza-Araiza, Amritpal Rehill

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[6] Popoola A, Keating A, Cassidy E. Alcohol cognitive impairment and the hard to discharge acute hospital inpatients. Ir J Med Sci 2008; 2: 141-5. .

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[8] Public Health England Dementia Profile

[9] Etkind, S.N. et al (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services BMC Medicine 2017 15:102

[10] Brayne C et al, Dementia before death in ageing societies – the promise of prevention and the reality, PLoS Med 2006;3; 10

[11] Dementia UK Update, second edition, Alzheimer's Society, November 2014

**Separate Appendices**

Appendix C – Executive Summary

Appendix D - Delivery Plan (being developed)