WEST SUSSEX
JOINT DEMENTIA STRATEGY

2020 TO 2023

EXECUTIVE SUMMARY

Developed in partnership with
West Sussex County Council and
NHS West Sussex Clinical Commissioning Group

CONTENTS

ACKNOWLEDGMENTS

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

Particular thanks goes to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains, 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.

FOREWORD

"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 Strategy has been developed in partnership with Health, Social Care, and District and Borough Councils and Community and Voluntary providers and includes direct input from people with the lived experience of dementia. It builds on the progress of our first dementia strategy, the Dementia Framework 2014-19, and the progress that has been made. The Strategy sits within the context of national and local policies, guidance and legislation.

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

Purpose of the strategy

To set out the plan for action over the next three years that builds on the work of the first dementia strategy and the progress that has been made with, for example, the rise in diagnosis rate, the offer of support for people living with dementia and their family and friend carers and with the development of dementia friendly communities.

Understanding the challenges

There are 4 main challenges we face:

1. **An ageing population.** Although dementia is not a natural part of growing older, it is more prevalent in people over the age of 65. The population of older people is set to rise in the next 10 years with the highest increase in people over aged 80 (60%). Older people are more likely to have 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.

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 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.

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

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 of dementia

Themed sub groups

Draft strategy consultation with stakeholders

Strategy update and sign-off

Where we are now

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

How we will get there

- To work closely with health, social care, community, voluntary and private providers and local people.
- For there to be a community-led approach to supporting the person with dementia and their families and carers and for there to be a commitment and willingness to innovation and learning.
- To enable the individual to live independently by helping them to see the value they bring and the resources around them rather than focusing on any negative characteristics.
- To work to a delivery plan which will support the goals of this Strategy and will include clear measures and points of review at regular intervals.

National Context

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

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

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

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

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 to be refreshed over the course of this strategy.

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

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

Sussex Community NHS Foundation Trust Dementia Strategy

Western Sussex Hospitals NHS Trust Dementia Strategy

THE NATIONAL PICTURE

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

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

850,000 people living with dementia in the UK

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

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

THE LOCAL PICTURE

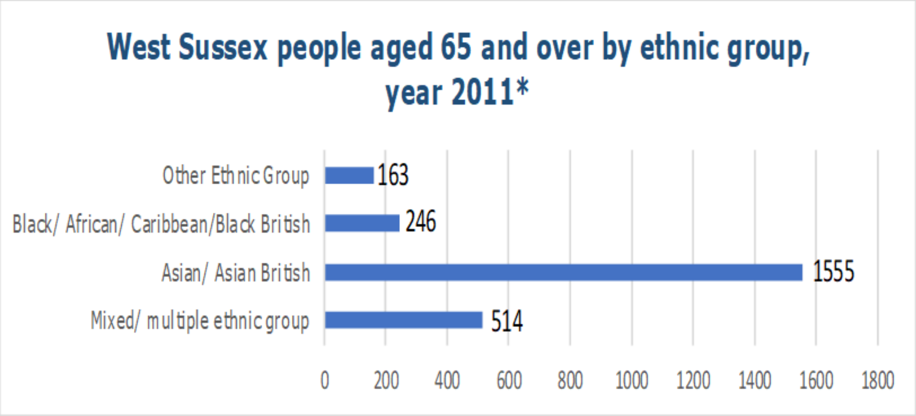
See **Appendix C** for a cartogram showing estimated population over age 65 with dementia at ward level

How dementia might look in next 10 years:

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**

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



*Figures are taken from 2011 Census

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

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

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

THE ECONOMIC COST

The number of people with dementia is set to rise considerably over the next 10 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 care from family and friends, social care and healthcare costs. Total cost is over £26bn.

West Sussex Projected costs of dementia by type of care (in £million)

	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, half of this number are aged over 85. There is a total weekly net cost of £290,000 and much of this cost (85%) is accountable for by long term residential and nursing care.

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

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

The need to ensure we continue to improve services to meet the needs of people affected by dementia is a high priority. However, the County Council and Clinical Commissioning Group are working with reduced public funding. It will be necessary for there to be 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.

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	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
risk of dementia is minimsed.	Timely, accurate diagnosis, care plan and review within first year.	Safe high-quality health & social care for people with dementia and carers	To live well in safe and accepting communities.	To die with dignity in the place of your choosing.

FAMILY AND 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."

- 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 risk of dementia 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 systems 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.

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 across the life course as identified in the Joint Health & Wellbeing Strategy. For example, educational attainment, physical inactivity etc.   **Families and carers of people with learning disabilities having access to information in an accessible format, at an early stage about the risks of dementia and the early signs of dementia.   **Greater risk to family and friend carers of loneliness and physical and mental health problems.

Diagnosing Well

"West Sussex County Council and the Clinical Commissioning Group 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."

- For some people a diagnosis of dementia may not be appropriate, or it may not be their wish to have a diagnosis but for many people receiving a timely diagnosis is key to ensuring they and their families and carers can plan ahead and access information advice and support. In West Sussex the pathway to diagnosis is normally through the GP who will refer the person to the Dementia Assessment Service (DAS) or Memory Assessment Service (MAS) once all reversible causes of cognitive decline are ruled out. The MAS/DAS provides a quality diagnosis and follow-up support for the patient and their family and friend carer. At this point, a care plan will be developed which provides an opportunity for the person to be able to draw on their own strengths and support around them and identify where additional support is required.
- The wait to diagnosis can often be a long and anxious one and it is important that during this time the person awaiting their diagnosis and their family and friend carers are supported. 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.
- Having good information and advice about support, welfare benefits and living with dementia, throughout the person's journey is key to ensuring people affected by dementia can live well with the condition. People should have access to information and advice, in a format that is right for them, at diagnosis and throughout their journey. There needs to be a 'no wrong door' approach to how people access information, where all information services provide the same level and quality of information.
- 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 recommends that people receiving a diagnosis should have a named coordinator who will be responsible for regular care plan reviews and have a good understanding of the person and their needs. They should also be able to navigate the health and social care system. In West Sussex, this is normally the person's GP.
- 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.

Key issues & challenges
Fear of stigma preventing someone accessing a diagnosis, more information about the benefits of diagnosis needed. **Early signs of dementia not being recognised in people with learning disabilities.Hearing and sight issues and other conditions can be confused with dementia. It is important for these to be ruled out before referral to the MAS/DAS.**Long waits to diagnosis.**Low rates of diagnosis in people from Black Asian & Minority Ethnic Communities (BAME) and people with Alcohol Related Dementia.**Issues with accessing information and advice later in the person's journey.**A system that is complicated and disjointed where people can get 'lost' in the system.**Care plans not being shared with all those involved in the person's care.**Services staying connected to the person living with dementia.

Supporting Well

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

- The person with dementia and their family and friend carer need to be put at the centre of the person's care and it is important for the individual along with those around them to have opportunities to plan ahead for their future care while they are still able to do so.
- People should know how to access support as their dementia progresses and organisations providing care and support need to work well together. This includes GP's, hospitals, social care, voluntary and community providers as well as the valuable support provided by many smaller community-led providers. 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.
- For many people, dementia is not the only long-term condition they live with and people need to have the support to manage the dementia and other conditions as much as possible for themselves.
- West Sussex County Council (WSCC) Adult Services, Proactive Care and Dementia services work together to help shift the balance of care away from reactive crisis intervention to independent health and wellbeing. They work to enable the individual to see the value they themselves bring as well as the resources around them. Services work together to help avoid an unnecessary admission to hospital and ensure people are discharged safely home as quickly as possible.
- The best place for someone living with dementia is to remain at home independently for as long as possible and having homes that meet the individual's changing needs is key to achieving this. House planning over the next few years needs to reflect the growing need and rise in prevalence of dementia. Housing providers can also play a key role by supporting Dementia Friendly Communities and ensuring their staff are dementia aware.
- 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. Technology-enabled services (TECS) such as telecare, telehealth and self-care apps can also help to support the person to live at home independently and can support the caring role.
- As the dementia progresses, some extra care and support to enable the person to live at home may be necessary. The Council continues to actively engage and support the market development of care and support at home providers and focus on building opportunities for developing local markets. Extra Care Housing can also be a good solution. Extra Care is a type of 'housing with care' which means the person can retain independence while being assisted with tasks such as washing and dressing or taking medication. The Council currently commission 12 out of the 13 Extra Care Schemes in the County.

- In West Sussex, the largest number of specialist dementia care homes is located in the Coastal area (55%) with only 5% and 9% in Crawley and Horsham respectively. For people who can no longer live at home, the Council has a responsibility for ensuring there is an offer of good quality residential and nursing care and sufficiency of supply. This relies on working with other partners including local planners, health, care providers and on staffing. There should be support available for the person and their families and carers to be able to make the right decision about their future care planning and how it will be funded.
- For people with dementia there is a greater risk of an unnecessary hospital admission, together with longer stays and delays to discharge.
- 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 confusing places for someone with dementia and sensitivity, compassion and understanding are core qualities that doctors, nurses and all hospital staff should have for their patients, as are listening and communicating. Hospitals in West Sussex have dementia training programmes in place that are targeted at all levels of staff.
- For family and friend carers, it is important for them to be able to access support for themselves whether it is they or the person they care for who is in hospital. Carers Support West Sussex has teams working within hospitals offering support with discharge planning and information and advice. 'John's Campaign', an initiative that ensures family and friend carers are treated as equal partners in the care of their loved ones, is also being run out of many of our hospitals.
- For patients leaving hospital, the Home from Hospital, Take Home & Settle and Relative Support services provide support for the person and their family.

Key issues & Challenges
Lack of clarity about eligibility for dementia services. People with dementia often have more than one health condition but health services do not always work in a joined up way.**Services designed to keep people at home are stretched and struggle to meet demand.**People with dementia from Lesbian, gay, bisexual and transgender+ (LGBT+) communities can feel services do not meet their needs.**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.**Unplanned admissions to hospital and longer stays resulting in loss of skills.**Delays in leaving 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.**Insufficient capacity within care market and challenges with recruiting care staff.**Overstretched resources.**Gaps in staff training and often lack of confidence in supporting someone with complex and challenging needs.

Living Well

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

- Dementia can compound feelings of social isolation and loneliness for both the person living with dementia and those caring for them. Research by Alzheimer's Society has found that people with the condition are more at risk of loneliness than the general population – with this risk increasing if the person with dementia lives alone.
- There is potential for the risk of loneliness and social isolation to be reduced and for people with dementia to live meaningful and satisfying lives. This requires support from all those people and services surrounding the person including their own community.
- There needs to be a community-led support approach to help meet the challenges faced. Community-led support that focuses on reaching people at an early stage is key to helping people affected by dementia to live well. This can help prevent or delay the development of their care and support needs and 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.
- Breaking down the stigma of dementia is key to ensuring people with dementia can live meaningful and satisfying lives. Dementia Friendly Communities can help people to access their local communities and reduce the risk of social isolation. Local Dementia Friendly Community Groups focus on changing public attitudes through the creation of dementia friendly communities. In West Sussex there are 10 Local Groups with members from local businesses, community groups, faith groups etc. Local Groups are led in the main by volunteers and this is unsustainable without the right support to build capacity. Without this support, over time dementia friendly communities may not be able to grow and develop. There needs to be a coordinated response to how Local Dementia Friendly Community Groups are supported and funded.
- Having good information and advice about support, welfare benefits and living with dementia, throughout the person's journey is key to ensuring people affected by dementia can live well with the condition. There needs to be a 'no wrong door' approach to how people access information, where all information services provide the same level and quality of information. In West Sussex, there is a universal offer of information and advice for people with dementia and their families from Alzheimer's Society's Dementia Support Service, Carers Support West Sussex along with a county-wide information and advice service commissioned by Public Health. A dementia zone on the West Sussex Connect to Support website provides information about dementia and local support.

- Caring for someone with dementia can put a huge strain on the carer’s physical and mental health. Family and friend carers should be offered training about dementia, its symptoms, providing care and the changes to expect as the condition progresses. 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. Information about services that can support the person in their caring role and planning for the future should be easily accessible and provided in a co-ordinated way.

  The Care Act 2014 gave councils enhanced duties towards carers and in West Sussex, carers are offered an assessment of their own need and have access to services such as carer short breaks, dementia cafes and drop-ins. 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.

- People living with dementia need to have access to a range of flexible activities that are of interest to them and promotes their wellbeing. They should be affordable and easy to get to and reflect their changing needs as the dementia progresses.
- In West Sussex, the Council, Clinical Commissioning Group, voluntary and community sector organisations and smaller groups and organisations provide a varied set of services that enable the individual and family and friend carer to live well. These can include daytime activities and short break respite opportunities to give the carer a break from their caring role. There is also an offer of emergency respite and support for people to settle back at home after a stay in hospital.
- People living with dementia and family and friend carers should also be able to take part in non-specialist/everyday activities, paid work, volunteering and learning new skills.
- Getting to groups and other activities can be particularly challenging for people living in more rural communities and there needs to be a plan for making sure there are better transport links and services that are closer to home.

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

Dying Well

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

- Conversations about future care should be had with the person with dementia and their family and friend carer as early on in their pathway as possible particularly about their wishes for their care at the end of life. This reduces the likelihood that difficult and emotional decisions have to be made in a crisis and/or when the person's wishes can no longer be taken into account. These type of conversations can often be difficult and it is important that staff involved in them have the necessary training to feel confident about starting the conversation with sensitivity.
- Planning with the whole family is important and where necessary, advocates need to be identified to support the person with health and welfare decision-making to ensure their wishes are reflected. In West Sussex, the Clinical Commissioning Group along with health services and local hospices have endorsed an Advance Care Plan called 'Planning Future Care'. This is being used to identify people's wishes and preferences for future care.
- To help navigate complexity at the end of life, open communication that involves patients and families in decisions, and is responsive to their needs is vital and can vastly improve their experience.
- People nearing the end of life need to receive coordinated compassionate care that is individual to their needs. This includes palliative care and bereavement support for the family. Care should be provided by skilled, trained and compassionate staff and family and friend carers throughout their life journey.
- 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 Coastal West Sussex, the End of Life Care Hub (ECHO) works proactively to support people in the last year of their life and provides a more responsive, proactive and individual offer of care.
- 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. 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.

Key issues & Challenges
Planning future care and end of life support not taking place early enough in the pathway. Advance care plans not being shared with all those involved in the person's care.**Hospital staff unaware of the person's end of life wishes.**People dying away from their usual place of residence or a place not of their choosing **Difficulty recognizing when someone with dementia is nearing the end of their life.**Lack of bereavement support.

Dementia in Different Groups of People

Early Onset Dementia

Younger people with dementia (under the age of 65) face different issues to someone older. There is often a long wait to diagnosis as other conditions are explored and support designed for older people is often unsuitable for someone younger and more active. This means that this group of people can often find themselves feeling isolated. The individual and their partner may still be working, they may have dependent children and older relatives to care for. The way they are supported must therefore be tailored to their specific needs.

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

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

Learning Disabilities and Dementia

People with learning disabilities particularly Downs Syndrome, have a higher risk of developing dementia than other people and usually develop the condition at a younger age. 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, this can delay the opportunity for early support. 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.

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 sensory loss 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

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

OUR GOALS

Our goals are based on the Dementia Well Pathway's five elements from the Prime Minister's Challenge on Dementia

Preventing Well

1. People live, work and play in environments that promote health and wellbeing and support them to live healthy lives.
2. Individuals, families, friends and communities are connected.
3. 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.
4. Early intervention and ongoing support for hearing loss.

Diagnosing Well

1. People recognise the early signs of dementia. They know what steps to take to receive a diagnosis and the benefits of diagnosis.
2. All groups of people to receive a timely diagnosis including younger people, people with alcohol related dementia, people with learning disabilities and people from minority groups.
3. Improved access to information and advice.
4. Improved access to good quality joined up support before and after diagnosis.
5. People have the opportunity to plan for their future care and contingencies along with those around them.

Supporting Well

1. For people to be enabled to live independently at home.
2. To reduce the risk of loneliness and social isolation for people with dementia living alone.
3. For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia.
4. Dementia and carer friendly health and care settings.
5. 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.
6. Compassionate care and support from staff skilled in dementia.
7. For support to be in place to avoid wherever possible unplanned admissions to hospital or inpatient facilities.
8. Where hospital admissions are required, for these to be as short as possible.
9. The risk of a crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support.
10. 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.

Living Well

1. 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.
2. There is a whole community response to living well with dementia in safe and enabling communities.
3. People can maintain and develop their relationships and be able to contribute to their community.
4. The risk of loneliness and social isolation for people with dementia living alone is reduced.
5. Carers of people with dementia are able to access information, support and training as needed and feel able to continue with their caring role.

Dying Well

1. People living with dementia together with their families and family and friend carers are enabled to make decisions about their future care.
2. People are supported to die with dignity in a place of their choice.
3. People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care.
4. Families and carers are provided with timely, coordinated support before death, at the time of death and bereavement.

A JOINT STRATEGIC APPROACH TO DEMENTIA

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

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

MONITORING DELIVERY & IMPACT ACROSS THE PATHWAY

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

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

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.

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.

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.

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.