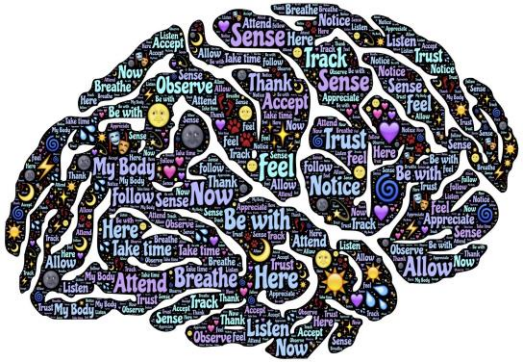


WEST SUSSEX
JOINT DEMENTIA STRATEGY
2020 TO 2023

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

west sussex county council

NHS

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 go to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains and Worthing Town Cryer's. Age UK West Sussex's K2 Club members, Sangam Women's Group and Carers Support West Sussex East Grinstead carers group.

FOREWARD

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

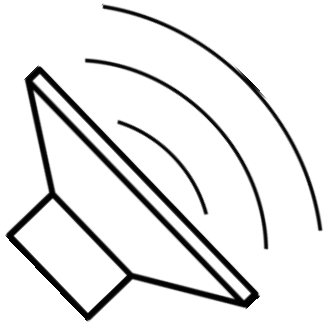
The County Council and the Clinical Commissioning Group are resolved to make West Sussex the best place to live well with dementia. This strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to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

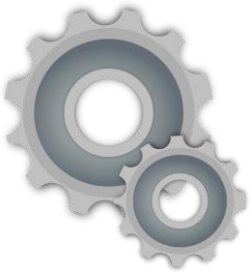
Promoting self-care and self-empowerment is often a primary requirement for those who want to stay in their own homes. Family and friend carers are influential in supporting those living with dementia and it is therefore key that we support them in their caring role. Carers tell us that their wellbeing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

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

Amanda Jupp

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





INTRODUCTION

This 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.

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.

Findings from the review of the Dementia Framework

Findings from a review of the current Dementia Strategy, the Dementia Framework 2014-19 in 2018, showed there had been improvements in diagnosis rates and the care and support people with dementia and their family and friend carers receive during their journey. It was noted though that there is still more that can be done to improve their experience. This strategy sets out what we plan to do about this.

The strategy builds on the work of the 2014-19 Dementia Framework and the progress we have made. It 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, 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

It is essential that a collaborative approach is taken across health, social care, community, voluntary and private providers, together with local people to achieve our objectives. Meeting the challenges faced needs a commitment and willingness to innovation and learning and there needs to be a focus on community led support, prevention and a strengths-based approach to Adult Services i.e. for an individual to be enabled 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.

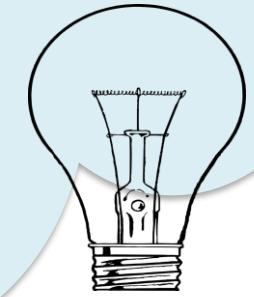
UNDERSTANDING THE CHALLENGE

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

1. An ageing population. With the rise in the number of people developing dementia over the next ten years set to rise, often with other significant and life-limiting chronic conditions. This means we should continue to look at how we can redesign and transform services and deliver more care and support in our local communities.

2. A timely diagnosis and consistent offer of person-centred, coordinated and flexible support for people living with dementia and their family and friend carers at every stage in their journey. This is key to ensuring people can live well with dementia.

3. Challenges within the care market 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
- Equality Impact Assessment
- 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.

People with dementia and their families and carers receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice.

People with dementia and family and friend carers have access to timely, skilled and well-coordinated support throughout their journey.

People with dementia and their family and friend carers receive care and support that focuses on an individual's strengths and looks to promote their wellbeing.

People with dementia, along with their families and carers are central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

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

WHERE WE ARE NOW

In 2018, a full review of the Dementia Framework West Sussex 2014-19 took place. It was led by the County Council and all three Clinical Commissioning Groups and included a public engagement with around 400 different people and organisations. 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.

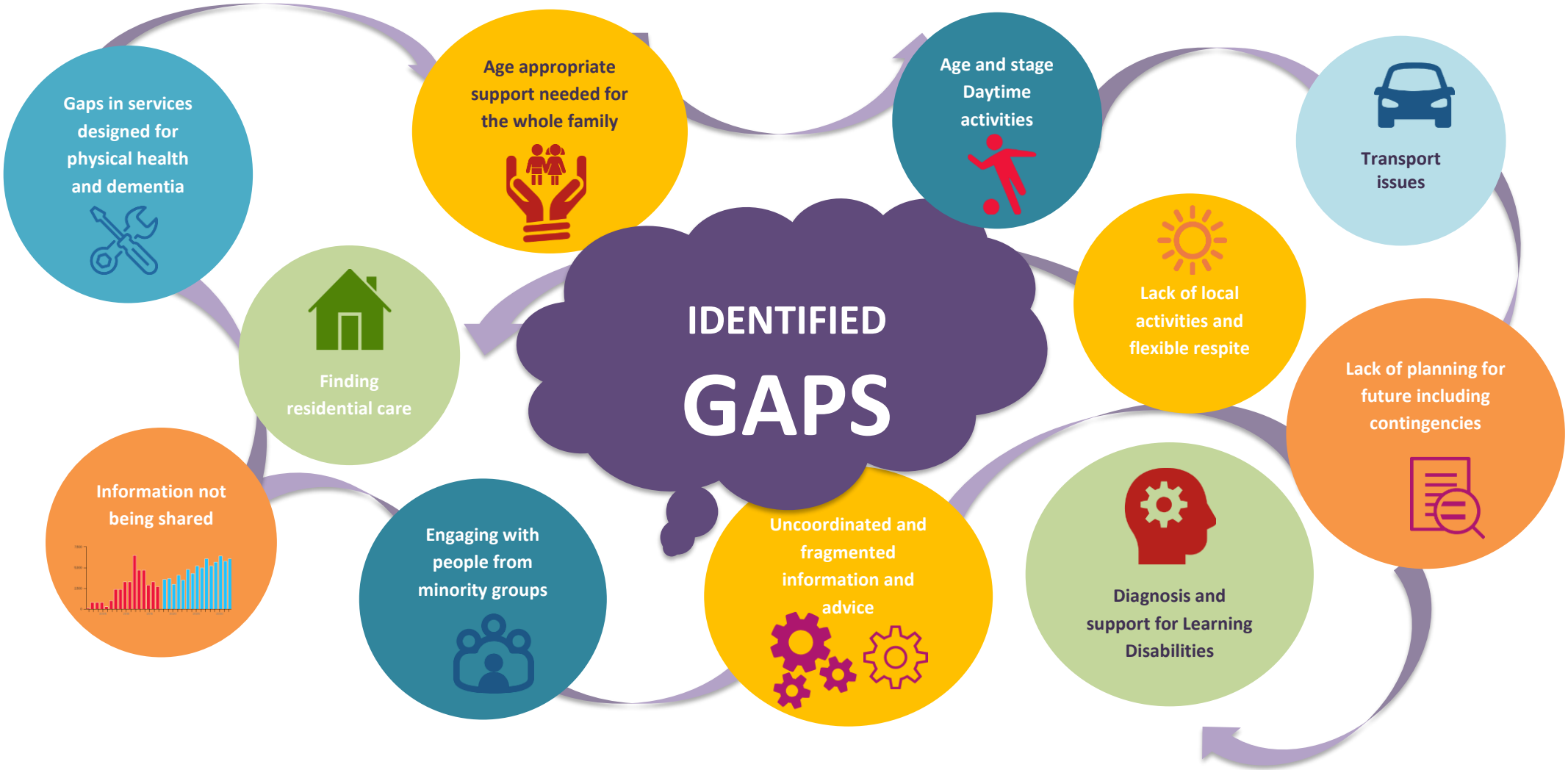
More people receiving a diagnosis and follow-up support. Around 20% more people are now receiving a diagnosis of dementia and the number of people registered with GP's has increased by 28%.

A more dementia-friendly West Sussex. 10 Local Dementia Action Alliances 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.

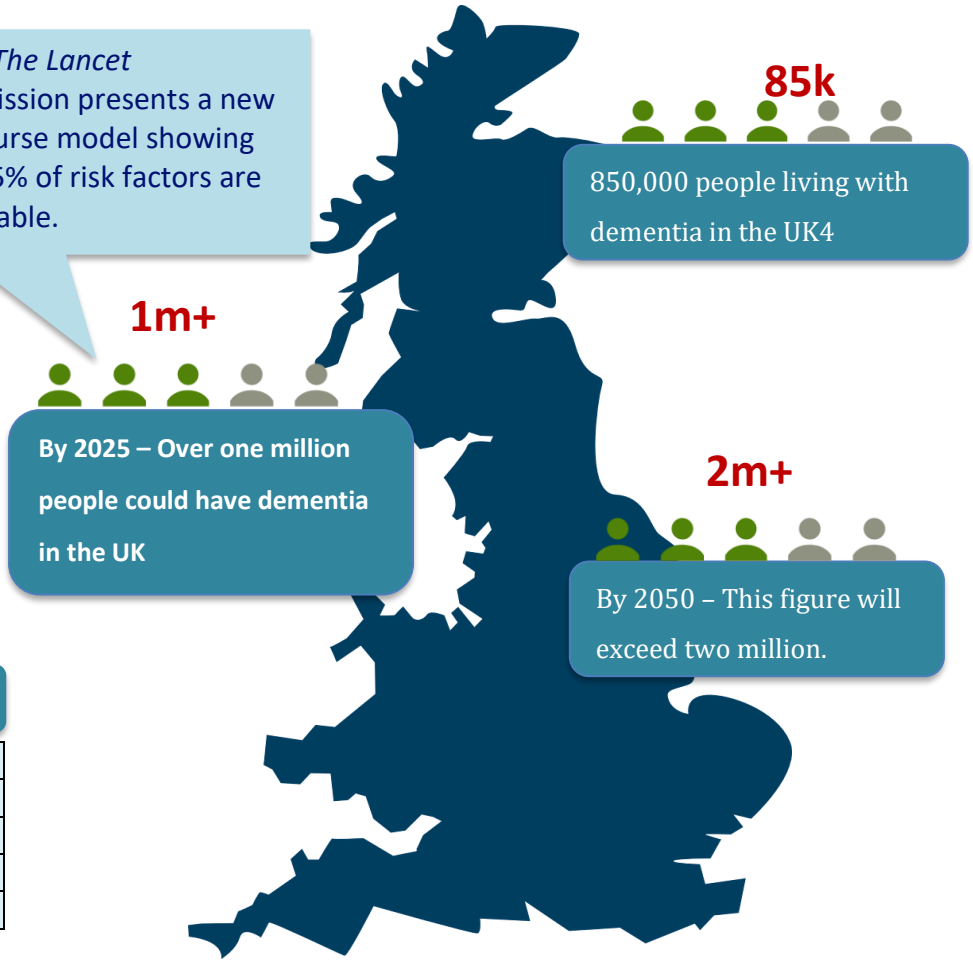
However, there is a significant number of people living in West Sussex with undiagnosed dementia and many people who feel unsupported following diagnosis. This document sets out what we plan to do about this.


IDENTIFIED
GAPS
Gaps in services designed for physical health and dementia
Age appropriate support needed for the whole family
Age and stage Daytime activities
Transport issues
Finding residential care
Lack of local activities and flexible respite
Lack of planning for future including contingencies
Information not being shared
Engaging with people from minority groups
Uncoordinated and fragmented information and advice
Diagnosis and support for Learning Disabilities

THE NATIONAL PICTURE

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.

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



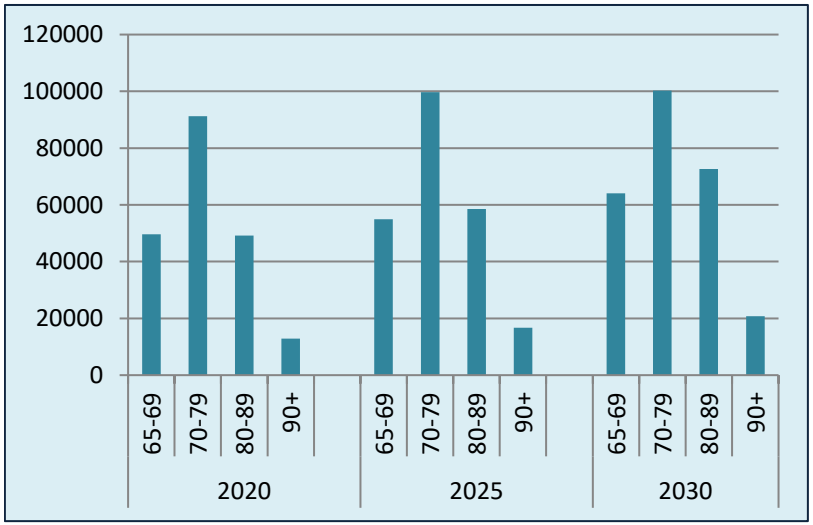
Projected number of older people living with dementia 2019-2040 England

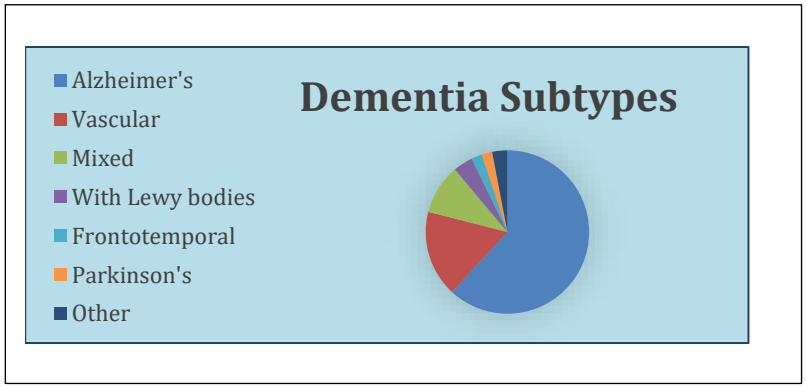
	2019	2020	2025	2030	2040	%change
Mild dementia	107,100	108,300	118,900	136,100	166,700	56%
Moderate dementia	206,300	198,900	210,100	235,600	276,100	34%
Severe dementia	434,600	461,900	569,400	674,400	909,600	109%
Total	748,000	769,200	898,500	1,046,100	1,352,400	81%

There are 850,000 people in the UK living with dementia, 42,000 of whom 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).[11]

THE LOCAL PICTURE

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





Highest increase is in people aged over 80

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

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

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

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

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

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

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

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.

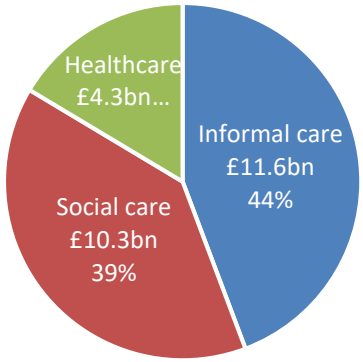
Sussex Community NHS Foundation Trust Dementia Strategy.

Western Sussex Hospitals NHS Trust Dementia Strategy

THE ECONOMIC COST

There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn[10].

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.



West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)[9]					
	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

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

The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition 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. The strategy has therefore been developed within the context of these financial restraints.

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 cares 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 Dementia Well Pathway has been used as a <u>foundation</u> for developing the goals of the West Sussex Joint Dementia Strategy 2020-23.

PREVENTING WELL

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

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, hypertension, depression and social isolation.

Key Issues & Challenges

- West Sussex is a county with easy access to good green spaces that provides opportunities for people to get more physically active.
- The perceived stigma of dementia can prevent people from going to their GP about symptoms they may be worried about. It is important there is good information available about the early signs and symptoms of dementia and positive messages about the benefits of diagnosis.
- Risk factors across the lifecourse approach as identified in the Joint Health & Wellbeing Strategy. For example, educational attainment, physical inactivity etc.
- The diagnosis rate for people from black and minority ethnic (BAME) communities has been historically low even though there is an increased risk of dementia for this group of people. More needs to be done to ensure there is good information about the risk factors, early signs of dementia and the benefits of diagnosis.
- 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 at an early stage about the risks of dementia and the early signs of dementia in an accessible format.
- 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. For Individuals, families, friends and communities are connected.	The prevalence of smoking is reduced across the county. The increase in people overweight or obese is reduced. More people aware of the impact that their alcohol consumption is having on their long-term health. More people becoming physically active. An increase in the number of people with learning disabilities receiving an Annual Health Check. 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. Carers are supported to remain physically and mentally well (West Sussex Joint Commitment to Carers 2015-20) There is greater public awareness about dementia and increased understanding to reduce stigma. 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. People accessing behaviour change interventions and programmes in mid-life are advised that the the risk of developing dementia can also be reduced. 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.
Early intervention and ongoing support for hearing 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. People need to be encouraged to take action when they think they may have hearing loss i.e. get their hearing checked and get hearing aids if appropriate.

PREVENTING WELL

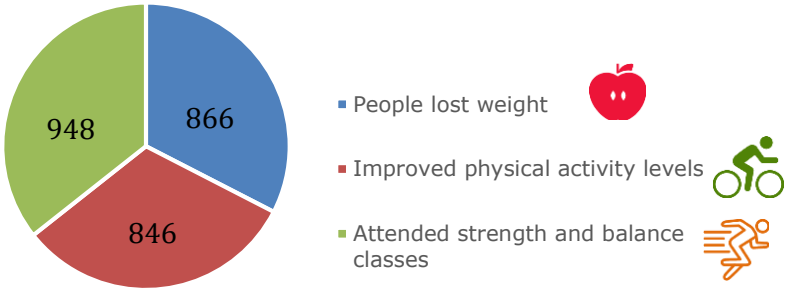
Local Key Initiatives/Examples of Best Practice**

- Public Health initiative/campaign - Ageing Well and Dying Well – compassionate communities.
- Local Wellbeing Walks.
- Coastal Care – Inspiring Healthier Communities Together
- Social prescribing service.
- Community sheds.
- Lifestyle related public health outcomes e.g. smoking prevalence etc.
- Wellbeing programmes and wellbeing deals: partnership arrangements between the County Council and District & Borough Councils.
- Health in all policies is an approach to public policies across sectors including housing, planning, transport etc.
- Public Health's Social Isolation and Loneliness project. For example, Adur & Worthing Council's Thriving Communities.
- Loneliness and social isolation is a priority area for action in the Age Well component of the West Sussex Joint Health and Wellbeing Strategy 2019-24.
- 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.
- Age UK West Sussex social clubs, gyms and fitness classes for older people.

**commissioned and non-commissioned services

KEY DATA

In 2017/18 948 adults were supported through the Wellbeing Hubs.



In 2017/18:

68% of adults physically inactive

62% adults classified as overweight or obese

13% of adults were smokers

20–40% of people with dementia will have depression.[11] Depression is more common in people with dementia than those without. Depression is also common among family carers

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

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.

*2017/18

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

For many people a diagnosis of dementia can be traumatic but for many people, it can also come as a relief. It helps people to plan ahead while they are still able to make important decisions. A timely diagnosis and follow-up support enable people with dementia and their family and friends the ability to maximize control over their lives and help to ensure that they can manage their condition, with the aim of ensuring they can live independently for longer.

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

Once people have received a diagnosis of dementia, they are provided with advice and given the opportunity to plan their future care along with those people who are important to them. 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 and is responsible for ensuring that the person diagnosed with dementia is linked into local support networks.

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

DIAGNOSING WELL

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 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 their particular needs.

Learning Disabilities and Dementia
People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s. 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. In West Sussex, the pathway to diagnosis is patchy. This could be down to the lack of baseline assessments taking place.

Black Asian & Minority Ethnic Communities (BAME) and Dementia
The review of the Dementia Framework identified the need for there to be more support for these communities. Among the UK's BAME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.

Alcohol Related Dementia
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.[2]

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.
- 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.
- The need for services to stay connected to the person living with dementia.

Our goals	What we mean
People recognise the early signs of dementia and know what to do to receive a diagnosis	Improved dementia awareness raising through dementia friends training, media communications, social networking. 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.
All groups of people to receive a timely diagnosis	• For all groups of people suspected of having dementia to receive 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. • The referral rate for people from BAME groups to reflect the ethnic makeup of that geographic area. • Support is available for the person being assessed and their families throughout the diagnostic process. • 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. 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 easily accessible throughout the person's journey and as their needs change.

Improved access to good quality joined up support following diagnosis	• People receiving a diagnosis of dementia from the DAS/MAS together with their family or friend carers receive an offer of support following their diagnosis. This should include an extensive group programme. • Family carers should be given the opportunity to speak openly about the diagnosis their loved one has received either with them or separately. 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 the future	• 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. • 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. • 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. • 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'. • 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

Local Key Initiatives/Examples of Best Practice**

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.

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.

Cognitive Stimulation Therapy Sessions

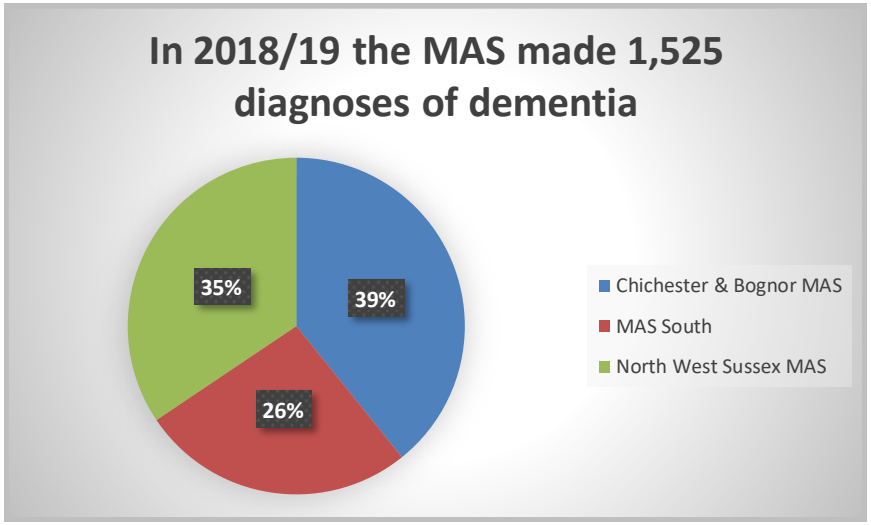
**commissioned and non-commissioned services

DIAGNOSING WELL – Key Data

3% of non-White British people diagnosed through the MAS in 2018/19

Post diagnostic interventions provided by MAS in 2018/19:
1251 people with dementia
990 family and friend carers

1233 referrals into the Dementia Adviser service in 2018/19



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

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

In 2018/19 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 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 readily access support without having to make multiple approaches. Adult Social Care, Proactive Care and Specialist Dementia Care Services are working together to help achieve this through coordinating care and shifting the balance of care away from reactive crisis intervention and unplanned care/hospital towards independent health and wellbeing.

There also needs to be a focus on community led support, prevention and a strengths-based approach to Adult Services.

People with dementia need to live in suitable housing that meets their changing needs with a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence.

The pattern of housing development needs to reflect the changing demographic within West Sussex, including the increase in numbers of people with dementia. Housing providers can play a key role in the development of Dementia Action Alliances and dementia friendly communities, and their staff can play a pivotal role in identifying the symptoms of dementia and encourage people to seek support. At the point of diagnosis, people may require housing advice to help them plan for later life.

As the condition progresses, it may become necessary for the person with dementia to require some extra care and support to enable them to live at home safely. In West Sussex, we continue to actively engage and support the market development of care and support at home providers to ensure excellent delivery for people accessing these services. We recognise 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. We continue to focus on building those opportunities for developing local markets and working with providers to continue to deliver this.

Extra Care Housing can be an attractive option 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.

SUPPORTING WELL

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. 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 stay in hospital for someone with dementia can be traumatic and confusing and there can be issues with eating, drinking and pain relief.

Services such as Dementia Crisis, Living Well with Dementia, Community Dementia Matrons and Admiral Nurses are working hard to support people who are at an increased risk of a crisis. 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.

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 at keeping people at home are stretched and struggle to meet demand.
- People with dementia from the LGBT+ community can feel that mainstream 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.
- People with dementia often experience longer stays in hospital, delays in leaving hospital and reduced levels of independent functioning.[3]
- 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 Young Onset Dementia.
- Over stretched resources including staff and time.
- Gaps in staff training and there is often lack of confidence in supporting someone with complex and challenging needs.

Our goals	What we mean
For people to be enabled to live at home	People have easy access to adaptations to the home and technology that allows people to live at home safely. For example, ramps, grab rails, movement sensors, personal alarms, trackers. People with dementia live in housing that meets their needs such as Extra Care Housing. For the risk of falls to be prevented that are caused through physical inactivity, poor hydration and nutrition, sensory impairment and home hazards. There is a co-ordinated offer of information, advice and guidance that enable people to have choice and control over their health and independence. 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.
For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia	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. The person with dementia and those around them need to be put at the centre of their care. 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. Service providers to ensure that information (such as care and support plans) can be easily transferred between different care settings. Patients should experience a smooth and timely transition from hospital back to their home environment. Hospital and community teams working together from admission, to tackle factors that could prevent a safe and timely transfer of care from hospital and to ensure the patient is at the heart of any discharge planning. 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.

Approaches to care and support that are individual to the person's needs	This means: • Building support around the individual with dementia, their carer and family and providing them with more choice, control and flexibility in the way they receive care and support – regardless of the setting in which they receive it. • Care and support are delivered in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities. • Ease of access to information and advice and advocacy services where there is not an appropriate person to represent the individual.
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: • identifying symptoms of dementia and know what steps to take to support people to receive a diagnosis. • acquiring greater awareness and understanding of dementia, so that they can help to ensure people are diagnosed and supported earlier. • becoming better equipped to help people in crisis to remain at home or return home after a hospital admission. • having awareness of the impact of dementia on the person living with the condition and their families. • 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. • 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. • Starting and holding difficult emotionally challenging conversations such as end of life care planning. 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. All healthcare assistants and social care support workers to have under undergone training as part of the national Care Certificate and staff competency and accreditation in dementia care skills should be regularly monitored and reviewed. For workers supporting people with learning disabilities to be skilled in supporting someone with dementia 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 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. 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.
The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support	The following contributory factors to a crisis should be identified and interventions provided where necessary:- • Family and friend carers unable to cope with their caring role. • The person with dementia presenting behavioural and psychological characteristics. • Physical health problems. • Social factors related to the person with dementia or their environment. 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. Where home treatment is not possible, patients should receive compassionate care by skilled staff, in dementia and carer friendly environments. 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.

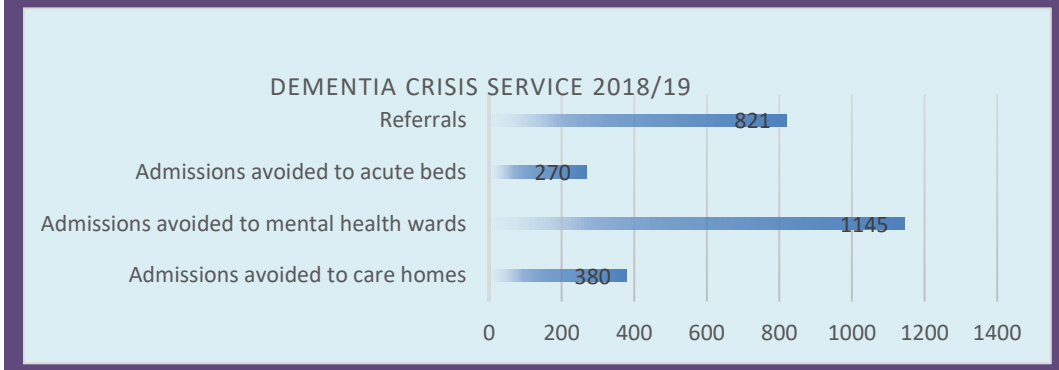
SUPPORTING WELL

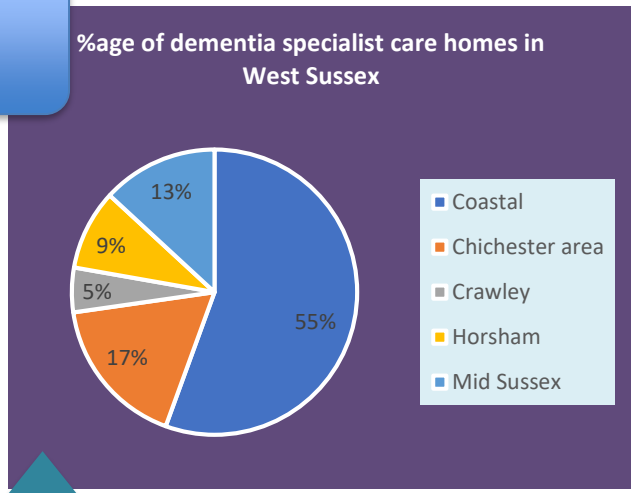
Local Key Initiatives/Examples of Best Practice**

- Information, advice and support for the individual and family and friend carers from Alzheimer's Society Dementia Support Service and Carers Support West Sussex.
- 'Hospital to Home' clinic at Horsham Hospital for providers to come and share information.
- 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.
- 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.
- Care & Business Support Service - A Council initiative that provides professional support to local services in the care sector.
- New Dementia In-patient facilities 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.
- WSCC Dementia Learning Framework on the Learning & Development Gateway.
- Procurement of the WSCC Care & Support at Home place-based service
- Time for dementia – Initiative to improve patient experience through increased dementia awareness in training for medical students.
- WSCC Technology Enabled Lives Service
- Dementia friendly hospitals charter
- Dementia champions across the Intermediate Care Units and considerable investment to improve environments.
- Dementia friendly Hospital Charter being rolled out by Western Sussex Hospitals Trust
- Robust dementia training programme for all hospital staff in West Sussex.
- 'This is About Me' and 'Knowing Me' tools to provide key information about individuals in hospital.
- A volunteer service 'Connect with dementia' at Crawley Hospital and Zachary Merton in Rustington
- An in-hospital Carer Wellbeing Service for family and friend carers through Carers Support West Sussex.
- 'Dementia Tour' – Immersive/interactive training for care staff.
- PatchCare® trialled by WSCC and Caremark. This initiative works with people living in their own homes and aims to create communities through care
- Home First – Discharge to Assess model. A service that enables people to be effectively and efficiently discharged from hospital.
- 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.
- 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
- Across the Coastal area people living with dementia can receive support with long term health conditions and social care needs from the community proactive care plus teams.
- Housing providers supporting tenants living with dementia.
- 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.

SUPPORTING WELL – Key Data

In 2018/19 5327 people used the Home from Hospital, Take Home & Settle and Relative Support services





In 2017/18 there were **2761 per 100,000 emergency admissions** for people with dementia* 848 less than nationally

*Dementia: Direct standardized rate of Emergency Admissions (aged over 65)[7]

Around **65 referrals each month** into the Dementia Support Service with 80% coming from family carers

13 Extra Care Housing schemes commissioned by the council

5,100 referrals to the Hospital carer wellbeing service in 2017/18

In 2017/18 there were 33.9% short stay emergency admissions of people with dementia over the age of 65[7]

132 residential and nursing homes specialising in dementia – offering 5104 beds

In 2017/18 Carers Support WS received 1293 equipment for independence referrals

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 Action Alliances (LDAA) 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. In West Sussex, there are currently 10 Local Dementia Action Alliances (LDAA) throughout the county 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.

The support offered family and friend carers is essential and 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 carers support services within the County, such as carer break services and more specialist services.

LIVING WELL

Local authority, clinical commissioning group, voluntary and community sector organisations deliver a diverse set of services including daytime activities and short break respite opportunities that provide a much needed break for the carer from their caring role. Services are provided 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.

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

Access to information and advice and support is key to ensuring all people affected by dementia can continue to live well with the condition. In West Sussex, there is a universal offer of information and advice for people with dementia and their family and friend carers from Alzheimer's Society's Dementia Support Service 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.

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 helps them to stay connected.
- Lack of flexible breaks for carers impacting on the carers ability to continue effectively in their caring role.
- There has been an 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 Young Onset Dementia to have support to engage in age appropriate activities.
- Sustainable Dementia Friendly Communities - Local Dementia Action Alliances 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 mainstream groups and activities.

Our goals	What we mean
People to have access to a range of affordable flexible activities that reflects their interests and needs	Dementia specific services or support to access mainstream activities to be designed to meet the needs of all people including those who: • do not have a family or friend carer • do not have access to affordable transport, or find transport difficult to use; • have sensory impairment or physical difficulties; • 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. 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.) Age appropriate activities or support to access mainstream activities for people with Young Onset Dementia and Alcohol Related Dementia.
There is a whole community response to living well with dementia in safe and enabling communities	• Sustainable communities that are inclusive of people living with dementia. • All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and action plans. • 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 • All employers with formal induction programmes including dementia awareness training within these programmes. • For younger people to be more educated and aware about dementia. • Public sector organisations taking a leadership role by becoming dementia friendly organisations. • 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. • 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. • Public transport that enables people with dementia to be able to participate in a wide range of activities and is welcoming and inclusive.

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. • 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. • For family members including dependent children of people with Young Onset Dementia to receive practical and emotional support.
Carers of people with dementia are able to access support 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. For family and friend carers to: • be offered an assessment of their own needs that considers their emotional, physical and social care needs. • have access to psychological therapies. • be identified by all those involved in the care and support of the person they care for and treated as partners in their care. • 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. • have access to education and advice about the most common problems they are likely to meet and how to deal with them. • have an opportunity to access one-to-one support and peer support so as to be able to link up with carers in a similar situation. • 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.

LIVING WELL

Local Key Initiatives/Examples of Best Practice**

- 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.
- WSCC in-house Shared Lives service for people with dementia.
- WSCC Compassionate communities project.
- Dementia Friends training.
- 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 Breaks twice a year north and south of the county, 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 from Fire Service.
- Carers Support West Sussex Dementia Wellbeing programme. Offers 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.
- Time to talk - intergenerational work with older people aged 65+ who experience feelings of chronic loneliness caused by social isolation.
- West Sussex Mind helping people over 65 in the Bognor and Chichester and Midhurst who are feeling low, have depression, anxiety or other mental health problem, or are simply feeling isolated.

**commissioned and non-commissioned services

LIVING WELL KEY DATA

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

10 Local Dementia Action Alliances in Arun, Burgess Hill, Chichester, Crawley, East Grinstead, Haywards Heath, Horsham District, Worthing, Selsey with a **membership of 282**.

5 WSCC Older People's Specialist day services – Glebelands, The Laurels, The Rowans, Chestnuts and Judith Adams

5 service user review panels hosted by Alzheimer's Society

32540 Dementia Friends in West Sussex and **127** champions

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 currently have around 25,000 registered carers and **almost 5,000 identify** themselves as caring for someone with dementia.

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 for advance care planning early on to ensure the person and their carer are fully involved in decisions on care at end of life.

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.

Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision making is crucial, to ensure 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 identify wishes and preferences for 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 and 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.

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.

DYING WELL

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 personalised 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.

Key Issues and Challenges

- People diagnosed with dementia are not supported to plan for their future care soon enough after diagnosis.
- Advance care plans where they exist 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.
- 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 health 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. • People assessed as not having capacity, with no family or friends are referred to an Independent mental Capacity Advocate as appropriate. 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. • People are not delayed from being discharged from hospital. • There is a framework for dementia training to ensure all people receive training relevant to their role. • 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.
People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care	• 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. • 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	• 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. • Families and carers receive bereavement support at a time that is right for the individual or family. • There is support and signposting available on the hospital ward for friends and family going through the grieving process.

DYING WELL

Local Key Initiatives/Examples of Best Practice**

- The End of Life Care Hub for Coastal West Sussex (ECHO)
- Ageing Well and Dying well - Compassionate communities. Public Health initiative/campaign.
- Clinical Commissioning Group's End of Life Providers Group
- 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.
- WSCC 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.

**commissioned and non-commissioned services

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.[7]

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[5]

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.

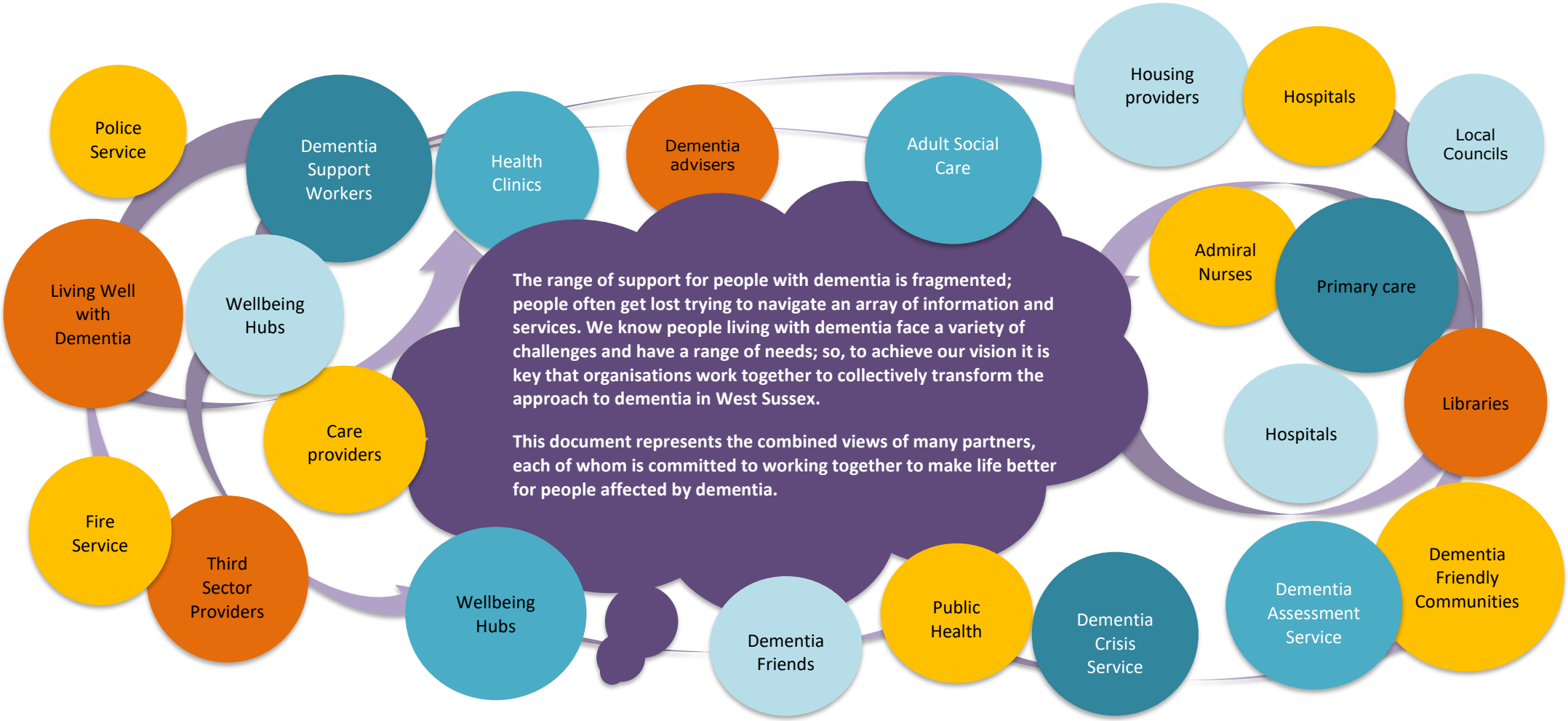
Average hospital length of stay in the last year of life for Echo patients was lower than for people who were not referred to Echo.

In 2017/18 **24%** of people aged over 65 in West Sussex died in hospital. 6% lower than nationally.[7]

In England and Wales, the number of people living with dementia who need palliative care will almost quadruple by 2040.[8]

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.[6]

A JOINT STRATEGIC APPROACH TO DEMENTIA IN WEST SUSSEX



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.

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.

Dementia Statements reflect the things that 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 shouldn't be treated differently because of their diagnosis.

Care - 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.

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.

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.

Carers - 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 Prime Minister's Challenge on Dementia 2020 (2015)

2 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. There is a need to ensure that there is therefore a clear pathway to diagnosis and post-diagnostic support for people in this group.

3 CQC 2017, DAA 2016).

4 Public Health England Guidance – Dementia – Applying all our health 2018

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

6 Dementia UK Update, second edition, Alzheimer's Society, November 2014

7 Public Health England Dementia Profile

8 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

9 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

10 Alzheimer's Research UK Dementia Statistics Hub

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

SEPARATE APPENDICES:-

Appendix C - 65+ Population with Dementia: Estimates by Ward

Appendix D – Executive Summary

Appendix E - Delivery Plan (to be ready by spring 2020)