Dementia Framework West Sussex 2014 ~ 2019

NHS Coastal West Sussex Clinical Commissioning Group

NHS Crawley Clinical Commissioning Group

NHS Horsham and Mid Sussex Clinical Commissioning Group

West Sussex County Council

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1.0 Foreword

We are pleased to introduce the West Sussex Dementia Framework.

It is estimated that there are 13,000 people living in West Sussex with dementia, and that this is set to grow by 14% by 2017, with a further 26% increase by 2021. This growth is happening at a time of significant reductions in public sector funding and we need to develop new ways to support people to live well with dementia.

Within West Sussex, we want people to be supported to maintain their independence for as long as possible. We want people with dementia, their families and carers to receive high quality, compassionate support, with timely diagnosis, access to good information and advice, and to live in supportive communities, where people feel able to participate in community life without stigma.

We want all people in West Sussex, including those from diverse communities, to receive integrated support that reduces the barriers between physical, mental health, social care and community based provision, where people with dementia, along with their families and carers are central to any processes or decision making and can express their own needs and priorities.

We will achieve these goals through partnership working with local people and across health, social care and community services, and by carrying out this dementia framework together.

The development of this framework is strongly based on the views, experiences and ideas of local people and organisations, and we wish to extend our sincere thanks to those who contributed to its development.

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2.0 Executive summary

The aim of this Framework is to set out the joint priorities for the provision of health and social care over the next five years for people with dementia, their families and carers. It is produced in partnership with West Sussex County Council, and Coastal West Sussex, Crawley, Horsham and Mid Sussex Clinical Commissioning Groups.

It is based upon the views of local people with dementia, their families and carers, providers, and health and social care staff. It is informed by national guidance, the West Sussex Needs Assessment for people with Dementia, and a review of evidence.

It sets out a clear vision:

- to improve the health and wellbeing of local people
- for those people who develop dementia to be supported to maintain their independence for as long as possible
- for people with dementia and their families and carers to receive high quality, compassionate support
- for people to receive timely diagnosis
- with access to good information and advice,
- for people with dementia to live in supportive communities, where they feel able to participate in community life without stigma.

The priorities are set around 7 themes:

- **Prevention** - both promoting healthy life styles to reduce incidents of vascular dementia, and raising awareness of dementia across the general public in West Sussex
- **Recognising there is a problem** – improving early diagnosis rates by working with staff from health, social, community and housing settings to identify symptoms and know what steps to take to support people to receive a diagnosis
- **Discovering the condition is dementia** – for people to receive a diagnosis in a timely manner and that they and their families and carers feel supported following diagnosis. For such support to be extended to people who received a diagnosis prior to the development of the Memory Assessment Service. For those diagnosed with mild cognitive impairment to receive proportionate follow up.

- **Living well with dementia –** to develop dementia friendly communities; to ensure that person centred, integrated approaches are taken by health and social care; that carers are supported in their roles with a range of flexible respite options available; facilitate a range of meaningful activity that also meets the needs of younger people with dementia. For people with greater support needs, there is: care at home available with skilled staff, that care in acute hospitals where ever possible avoided, but where this is required, the length of stay for people with dementia is as short as possible, and that steps are taken to enable people with dementia to receive compassionate care by skilled staff in dementia friendly environments; there is sufficiency of quality residential provision for those who can no longer be supported at home.
- **Getting the right help at the right time –** ensure that people with dementia, their families and carers have access to the right information at the right time, by developing clear points of contact as people progress with their dementia, developing a single dementia website linked to Connect4Support, with printable leaflets for those who cannot access the internet; to ensure that all people registered with dementia are supported to complete a contingency plan that seeks to where possible support people to remain in their own homes and that there are consistent levels of dementia crisis support across the County; that people are able to access technology that supports them to maintain their independence, for example with use of assistive technology.
- **Nearing the end of life –** to support the roll-out of advance care plans, and that staff are trained to understand the importance of such care planning and how to support people with dementia and their carers throughout the end of life stage.
- **Support to engage with research** – local people know how to participate in research should they so choose.

How we will get there?

It is essential that a collaborative approach is taken across health, social care, community, voluntary and private providers, in conjunction with local people to achieve the objectives within the framework. It will be supported by an implementation and investment plan with clear measures and points of review to ensure that the intended aims are being achieved.

3.0 Introduction

Dementia is defined as:
a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.

Alzheimer's Society

This framework has been developed jointly by the Coastal West Sussex, Crawley, Horsham and Mid Sussex Clinical Commissioning Groups (CCG) and West Sussex County Council (WSCC), in partnership with a wide range of local people, community and voluntary organisations.

The purpose of the framework is to let local people and organisations know about services that are provided now, and how they will change or develop over the next five years to reflect the views of local people, legislation, policy and the resources available. It will set out goals to help people live well with dementia, with ways to measure whether these have been reached.

This framework sits within the context of national and local policy including the National Dementia Strategy (Department of Health (DH) 2009)[1], the Dementia Pathway and Quality Standard (National Institute for Health and Care Excellence (2010)[2] and the Dementia – A State of the Nation Report (DH 2013)[3]. It links with WSCCs priorities around start of life, economy and later life, as well as other local strategies including the West Sussex Health & Wellbeing Strategy 2012-2015, and joint frameworks relating to personalisation, carers, people with functional mental health problems and for people with learning disabilities that are currently in development.

[1] Department of Health (2009) Living Well With Dementia: a national dementia strategy COI: London
[2] National Institute for Health and Care Excellence (2010) QS1 Dementia Quality Standard http://publications.nice.org.uk/dementia-quality-standard-qs1
[3] Department of Health (2013) Dementia A state of the nation report on dementia care and support in England Williams Lea for the Department of Health: London

The framework is based upon a Public Health evidence review of the interventions that support people with dementia to remain independent, as well as the forthcoming Needs Assessment for people with dementia. This outlines the increasing number of people that are likely to develop dementia within West Sussex, and is at a time when both the NHS and WSCC need to make significant cost savings.

Within this financial climate, it is essential that organisations and communities across West Sussex work together to achieve the strategy and provide high quality, compassionate support, whilst reducing stigma.

To this end, the key purpose of the framework is to set out a basis for organisations and people across West Sussex to work together to achieve a shared vision, where people can say that:

- I was diagnosed in a timely way.
- I know what I can do to help myself and who else can help me.
- Those around me and looking after me are well supported.
- I get the treatment and support, best for my dementia and life.
- I feel included as part of society
- I understand so I am able to make decisions
- I am treated with dignity and respect.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know how to participate in research

Dementia – a state of the nation report on dementia care and support in England.

4.0 Vision

Our vision for West Sussex is 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 should receive high quality, compassionate support, with timely diagnosis, access to

good information and advice, and to live in supportive communities, where people feel able to participate in community life without stigma.

We want people to receive integrated support that reduces the barriers between physical, mental health, social care and community based provision, where people with dementia, along with their families and carers are central to any processes or decision making, and where ever possible are helped to express their own needs and priorities.

At a time of financial austerity, this will take significant and collaborative efforts across health, social care and communities.

5.0 Where are we now?

Building on the National Dementia Strategy, organisations across West Sussex have worked jointly to improve the experience of people living with dementia, their carers and families. Key achievements include:

5.1 Timely diagnosis - with a memory assessment service, which includes assessment, diagnosis, on going support from dementia advisers, medication reviews and carer training.

5.2 Integrated dementia crisis teams – operating across West Sussex, providing a health and social care response to crisis including 72hrs of intensive support and up to six weeks of domiciliary care and respite.

5.3 The care home in reach service - working with care and nursing homes across West Sussex to improve practice, cascade training, undertake medication reviews for residents and support the homes to improve environments and meaningful activities for residents.

5.4 Improved care in hospitals - the shared care ward at Princess Royal Hospital has gained local and national recognition for good practice, using a partnership approach with both physical and mental healthcare staff, an environment

designed for people with dementia and regular groups and activity work for patients and carers. Mental health liaison teams also support nursing staff to care for people with dementia in acute hospitals.

5.5 Dementia alliances - growing across West Sussex, the most developed of these is the Crawley Dementia Alliance, and an alliance co-ordinator is in post to replicate the success in Crawley to other towns in West Sussex.

5.6 Assistive Technology – people with dementia in West Sussex can access a thirteen week free trial of community alarm and linked sensors, where a professional assesses that this could avoid hospital admission or facilitate early discharge. Following a successful trial, there is also now a universal offer to carers for assistive technologies that can help reduce the burden of caring, for example, bed sensors and automated reminders.

5.7 Carers support – across 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.

5.8 Residential Care - It is estimated nationally that one third of people with dementia live in residential care, and about two thirds of people who live in care homes have dementia[4]. Currently WSCC provides funding for approximately 1,400 people with dementia for residential placements. This breaks down to approximately 1000 placements in the Coastal area; 150 in the Crawley area; and 250 in the Horsham and Mid Sussex area. WSCC also directly provides a residential resource centre within Worthing that provides long stay and respite places for twenty people with dementia at any one time. WSCC commissions Shaw Health Care to deliver residential care for people with dementia within ten care homes.

The level of dementia care home provision differs noticeably by district across West Sussex. During a recent survey of vacancies, there were no vacancies at the WSCC funded rate in the Crawley area, and only 40 vacancies county wide. Without action to reduce the need for residential care or an increase in availability, there is a risk that people requiring WSCC funded placements may need to move greater distances and/or that the cost of provision may escalate.

[4] Dementia – A state of the nation report on dementia care and support in England (Department of Health 2013)

5.9 Day Services - WSCC currently run seven specialist day services that are accessible for people with dementia. WSCC also commissions Shaw Health Care to provide day services provision across a further five sites.
People with dementia also access a range of voluntary and community day services and activities, of which some receive grant funding from WSCC.

6.0 Views of stakeholders

In developing the Framework, it was imperative to engage with West Sussex people who have dementia, their families and carers, as well as staff and organisations involved in delivering services, in order to collect and collate their views, opinions, experiences and perceptions. Direct quotes from this are included in this framework. The engagement also needed to provide opportunities for people with protected characteristics to ensure equity in developing the Framework.

Avenues to allow people to contribute included focus groups and personal journeys facilitated by five voluntary organisations, responses to articles in the newspaper, emails, telephone calls, visits to local libraries, surveys, staff focus groups, stakeholder events as well as looking over new local and national research, co-ordinating questions with other projects underway, accessing social care blogs and re-analysing existing relevant surveys.

The Framework builds upon the main themes coming out of the engagement. A full report can be found in the JSNA Dementia Needs Analysis. In summary though, people frequently expressed the following views:

- Confusion about who does what, including with regard to voluntary organisations.
- A request for a "One Stop Shop" co-ordinated approach.
- Difficulty in finding information and knowing what you need to know at right time, with requests for an information system, including an information pack.
- Some people found support groups helpful, but were also requesting personal one to one service with the potential for a "buddy" system and time to talk.
- Issues of isolation were highlighted by some, which was exacerbated by either lack of available transport or living in a rural area.
- Concerns were raised about the funding of services and the impact the economic situation might have on availability of resources.

- Some people described positive experiences, but others felt unsupported and described difficulty with communication with and between services.
- Requests for more education of the public about dementia to "normalise" the illness.
- Concerns about the potential impact of caring on the carer.
- Concerns being raised about the journey from home into residential care.
- Sufficiency of quality flexible respite and day care provision.
- Requests to listen to carers more, possibly in actually monitoring services.
- Difficulties for self-funders

During the same period, West Sussex County Council also completed the national bi-annual carers survey. Almost half of the people who responded cared for someone with dementia. It highlighted that in comparison to all other carers, being a carer for someone with dementia made people significantly more likely to report worries about their safety; insufficient emotional support; social contact; and found it more difficult to do enough things that they enjoy with their time or having enough control over their daily life. This is a key area of focus for this framework.

All of the work with stakeholders shows that people want West Sussex to be amongst the best for dementia care and awareness, and a county where people with dementia and their carers can say the 'I' statements set out in the introduction.

7.0 Needs Assessment

The Joint Strategic Needs Assessment indicates that there are currently estimated to be over 13,000 people living with dementia in West Sussex. Of these, around 1,700 people are estimated to have severe dementia. It is thought that approximately 62% of people with dementia have Alzheimer's Disease, 17% have vascular dementia, 10% have a mixed Alzheimer's and Vascular dementia, with the remainder having either Lewy Bodies, Frontal Temporal, Parkinson's or other type of dementia. Age has a clear relationship with both the severity of symptoms and the probability of living in a care institution, but dementia is not an inevitability of aging. While most cases of dementia are related to Alzheimer's Disease, vascular dementia (often related to unhealthy lifestyle) is thought to cause between 15% and 35% of cases. Whilst it is essential to promote the benefits of healthy lifestyles, the impact of public health programmes is unlikely to result in a significant reduction in incidents or associated costs over the next five years.

West Sussex has one of the oldest populations of any local authority in England and the number of older people is expected to grow as a proportion of the population year on year for the next 20 years, with particularly high growth in those aged over 90.

Data in Jan 2013 estimated that 45% of those living with dementia had received a diagnosis and were on GP registers. This varied between 16% and 108% of modelled prevalence by GP practice, it should, however be noted that the presence of care homes is suspected to have a large influence on these rates, that there are data quality issues and that significant improvements to diagnosis rates may have been made over the course of 2013.

8.0 Economic Model

The approximate cost of mental health provision for people with dementia in West Sussex is £18million per year. WSCC currently spends around £23million on care for people with dementia, £14million of which was identified as 'dementia specific' spend, over and above the total costs of other social care needs. Findings from an economic model produced by WSCC predict that changing demographics alone would lead to a 25% increase in social care spend on people aged over 65 between 2013 and 2021.

The findings from the model suggest that the County's Memory Assessment Service is highly likely to be cost effective and improving diagnosis rates from 45% to 60% may lead to moderate savings over 8 years, but it should be noted that such savings were not forecast in all of the scenarios considered. The model also analysed the financial impact of people moving to West Sussex from other areas, and this indicated an increase in social care costs of £17 million over the same time period.

However, savings from improved diagnosis rates are small when compared to the demographic effect. WSCC currently support 23% of people aged over 90 years old in the county, at an average cost of over £8,000 per person, with much of that cost being accounted for by long term residential care. With numbers of people in this age group expected to increase by 36% between 2013 and 2021, WSCC must focus resources on keeping people independent for longer.

9.0 Priorities: Based upon the engagement with a wide range of people, the joint strategic needs assessment, economic model and an evidence review the following priorities have emerged.

9.1 Prevention:

Evidence shows a link between healthy lifestyles and a reduction in the likelihood of developing vascular dementia caused by strokes. It is important to give people information and advice that improves awareness of the benefits of both good physical and mental health and well-being, so that people can make healthier decisions that in time will reduce the number people who are affected by dementia and increase the age of onset. This needs to be for all groups of people including those from black and ethnic minority (BME) groups who have been shown to be at greater risk of developing vascular dementia[5]. Prevention is unlikely to reduce incidents of vascular dementia or produce savings during the period of this Framework. However, long term, it may result in reduction in prevalence.

Phase	Area	Outcome	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Prevention	NHS Health Check Programme	To increase awareness of the signs of dementia for people over 65 and to help people understand how they can reduce their risks of developing vascular dementia	All NHS Health Checks for over 65s to include information on how to reduce the risk of vascular dementia	I know how to reduce my risk of developing dementia and how to get help to live a healthy life style	Increased awareness of dementia and long term reduction in the incidents of vascular dementia (impact likely to be beyond 2019)
	Targeted support for BME groups	To increase proportion of people who lead healthy lives, to reduce incidents of vascular dementia	To ensure that the take up of wellbeing programmes reflects the BME makeup of the local community	I know how to reduce my risk of developing dementia and how to get help	Uptake of wellbeing programmes reflects the

[5] Social Care Institute for Excellence (2011) *Research Briefing 35*

		beyond 2019 in BME groups		to live a healthy life style	BME makeup of the local community (impact likely to be beyond 2019)
	Stop smoking advice and tobacco control	To reduce the prevalence of smoking across the county to 18.5% or less in adults, 11% or less in pregnancy, 12% or less in 15 year olds.	A comprehensive tobacco control programme, that delivers support to those that wish to quit and actively encourages those that don't smoke not to start.	I know how to reduce my risk of developing dementia and how to get help to live a healthy lifestyle.	Long term reduction in the incidents of vascular dementia (impact likely to be beyond 2019)
	Healthy weight	To reduce the increase in over weight and obesity	An integrated healthy weight care pathway that considers the intergenerational issues of weight.	I know how to reduce my risks of developing dementia and how to get help to live a healthy lifestyle.	Long term reduction in the incidents of vascular dementia (impact likely to be beyond 2019)
	Alcohol harm reduction	To increase the number of people who are aware of the impact that their alcohol consumption is having on their long term health.	Public awareness communication campaigns and on line brief interventions triggering personalised action plans.	I know how to reduce my risks of developing dementia and how to get help to live a healthy lifestyle.	Long term reduction in the incidents of vascular dementia (impact likely to be beyond 2019)
	Physical activity	To increase the number of people who are achieving the Governments recommendation of 150 minutes of physical activity a week.	Reaching Rio a workplace physical activity challenge. Physical activity programmes targeting the most sedentary, through the wellbeing programme delivered at district level.	I know how to reduce my risks of developing dementia and how to get help to live a healthy lifestyle.	Long term reduction in the incidents of vascular dementia (impact likely to be beyond 2019)
	Annual Health Checks for people with	To enable easier diagnosis of dementia for people with learning disabilities	Explore opportunity to use annual health checks for those people over 35 years old with	I was diagnosed in a timely way	Increase in the proportion of people with

	Learning Disabilities		a learning disability to record people's level of functioning and consider whether any reduction in ability may be linked to the development of dementia		learning disability and dementia who have a diagnosis
	Raise awareness of Dementia across the general public in West Sussex	To increase proportion of people who are aware of the symptoms of dementia and know what steps they can take to reduce stigma and help people with dementia access support	Combined communication strategy to increase awareness of dementia and the steps to take, that also considers ways to raise awareness in BME groups	I know what the signs of dementia are and who to contact if I have concerns	Increased take up of referral to memory assessment service

9.2 Phase 1 - Recognising there is a problem:

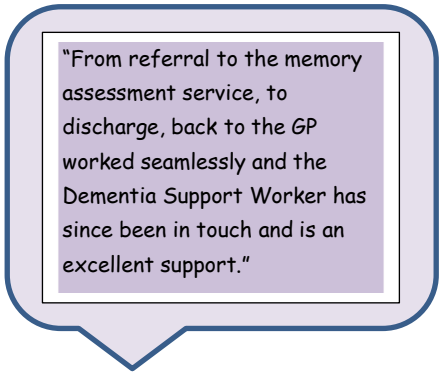
Receiving an early diagnosis enables people with dementia, their families and carers to make decisions, plan for the future and get the support they require. People need information to help them recognise and understand dementia and know what support and options are available to them. Evidence also demonstrates benefits of workers in different settings such as housing support understanding what signs to look out for and how to enable people to access an early diagnosis. When issues are identified, health professionals, such as GPs need to respond consistently, with onward referral to the Memory Assessment Service and carers support services where indicated

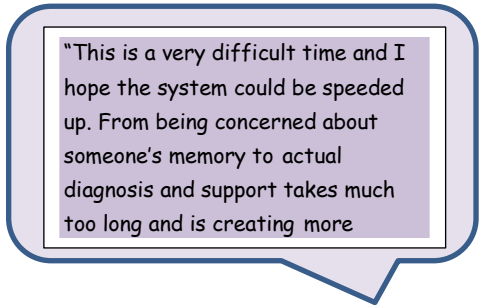
Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Recognising there is a problem	Improve early diagnosis rates	Two thirds of people with dementia receive a diagnosis	For GPs and practice nurses to use long term conditions clinics and health campaigns (eg: seasonal	I was diagnosed in a timely way	Two thirds (66%) of people with dementia who have

			flu) to consider with older people at risk of dementia whether they have any symptoms that may require further consideration. GPs to review older people in residential care homes to consider whether a diagnosis of dementia is indicated. For GPs to respond to concerns about dementia in a consistent way, with onward referral to the Memory Assessment Service.		a diagnosis, and that this rate is consistent across GP practices
	Training for staff working in health and social care, community and housing settings	Skilled health and social care staff that are able to identify symptoms of dementia and know what steps to take to support people to receive a diagnosis	Facilitate integrated approach to training that enables all staff working with older people to be able to identify the symptoms of dementia and know how to help people to access a diagnosis	I was diagnosed in a timely way and I get the treatment and support best for my dementia and my life	Training programmes are available to all health, care, community and housing settings, with a good uptake (to be defined)

9.3 Phase 2 - Discovering that the condition is dementia:

The aim is to ensure that two thirds of people with dementia receive a diagnosis and appropriate post diagnosis support, with referral to a Memory Assessment Service that will continue to provide people with dementia, their families and carers support via Dementia Advisors and Dementia Support Workers or other suitable carers support service. This will enable people with dementia and their carers to maximise the control over their lives and help to ensure that they can manage their condition, with the aim ensuring people can live independently for longer.





Those people and their carers who were diagnosed prior to the start of the Memory Assessment Service will also be able to access similar support. This will require an increase in resources in this area, as this is currently a gap in provision.

All groups should benefit from such early diagnosis and support, including younger people, those who have learning disabilities, or are from BME groups. A clear pathway will also be defined for those with alcohol related dementia.

Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Discovering the condition is dementia	Memory Assessment	People to receive a diagnosis in a timely and supportive manner	Memory Assessment Services that provides a quality diagnosis within a specified number of weeks for a proportion of referrals, and is equipped to diagnose people with learning disabilities and younger people, and provide support for other clinicians to provide a diagnosis where the full memory assessment process would not be in the best interests of the person showing signs of dementia. To ensure that the referral rate for people from BME groups reflects the ethnic makeup of that CCG area. For people to continue to be offered anti-dementia	I was diagnosed in a timely way	Number of weeks it takes from referral to diagnosis with proportion of people who expressed they were satisfied with the way this information was shared.

			medication when it is indicated that this is medically appropriate.		
	Alcohol related dementia	For people with alcohol related dementia to receive timely diagnosis and support with clarity about which professionals should provide this	To develop a clear pathway for people with alcohol related dementia to access help	I was diagnosed in a timely way and I get the treatment and support best for my dementia and my life	Pathway established that is recognised by health and social care staff, and that they report an improvement in the process of diagnosing people with alcohol related dementia and support.
	Support for people who are deaf or hard of hearing or have visual impairment	To ensure that people who develop dementia and are deaf or hard of hearing or have a visual impairment are identified, with correct support and where appropriate onward referral	For Memory Assessment Service to consider the needs of people that are deaf or hard of hearing or have a visual impairment, and to routinely consider onward referral to minimise the impact of hearing loss or visual impairment. Dementia training for staff to incorporate the additional complexities of having dementia and being deaf or hard of hearing or having a visual impairment and the steps to take to support people	I get the treatment and support, best for my dementia and life. I feel included as part of society	That hearing loss and visual impairment is routinely considered for people diagnosed with dementia. Training promotes understanding of this additional complexity.
	Support after	People, their	Memory Assessment Service	I know what I can do to	Proportion of people

	diagnosis	families and carer feel supported following diagnosis and are able to plan and have control	to provide information and advice about the condition to the person with dementia, their families and carers; coordination of activities for people with dementia; and work to reduce the stress and anxiety of people living with dementia and their carers, regardless of whether the diagnosis was made by the Memory Assessment Service or by another appropriately supported clinician	help myself and who else can help me. Those around me and looking after me are well supported. I get the treatment and support, best for my dementia and life. I feel included as part of society.	with dementia, their families and carers who express satisfaction with the support they receive after diagnosis.
	Support to those who were diagnosed before the introduction of the Memory Assessment Service	People, their families and carer feel supported following diagnosis and are able to plan and have control	Extend availability of this support to cover those diagnosed prior to the introduction of the Memory Assessment Service and are not in receipt of other specialist mental health support	I know what I can do to help myself and who else can help me. Those around me and looking after me are well supported. I get the treatment and support, best for me dementia and life. I feel included as part of society.	People who access this support express satisfaction with the service provided.
	Mild Cognitive Impairment	For people with mild cognitive impairment to feel supported and identify those who are at risk of developing	Information and advice is provided to people with mild cognitive impairment with proportionate review to monitor where symptoms appear to be progressing	I was diagnosed in a timely way	Proportion of people with mild cognitive impairment that receive proportionate follow up.

		dementia			

9.4 Phase 3 – living well with dementia:
Part A - For all people with dementia, their families and carers

"We should all do what we can to support the growth of dementia friendly towns and communities in West Sussex"

9.4.1 Dementia Friendly Communities - Excellent progress has been made in some areas to enable West Sussex to be dementia friendly, with Crawley being recognised as one of the best examples in the country. The Dementia Forums across West Sussex will continue to work together to affect similar changes, so that there is a high level of public awareness and understanding that enables people with dementia to seek help and be more able to continue to carry out day to day activities, that will enable them to live independently for longer. They will also seek to incorporate more residential care homes that specialise in dementia provision, so that their residents can benefit from the assets in their community.

"Services need to have a more caring attitude"

9.4.2 Person centred approaches – this is fundamental to the delivery of health and social care support, right from the early stages of diagnosis through to end of life care. People need compassionate support that maximises the opportunity to have control over the decisions that affect their life, and are enabled to consider how they would like to be supported as their condition progresses. People with dementia, their families and carers need to be put in the centre of their care, with access to flexible support that is responsive to their personal interests and needs, whilst encouraging independence and control in the decisions they make.

"Every person's experience with dementia is different. Services need to listen to what people want, not presume to know what is wanted."

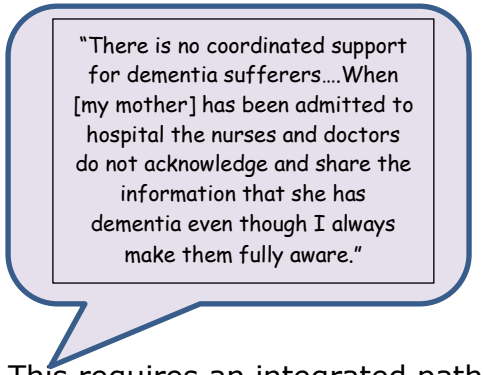
To do this people need[6]:

- to have access to quality information about dementia and the supports available;
- to have access to advocacy;

[6] Drawn from Think Local Act Personal *Making it Real for People with Dementia* (2013)

- information about community activities, leisure and transport, including the benefits of keeping connected with others;
- front-line health and social care staff that work in a person-centred way, with organisations investing in dementia training;
- support to engage in meaningful activity, doing something that they enjoy or are interested in.
- organisations that access the skills in the wider community

Work will also be undertaken to develop a diverse provider market that builds on best practise to enable both self-directed support and the delivery of culturally sensitive support.



9.4.3 Integrated approaches - 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.

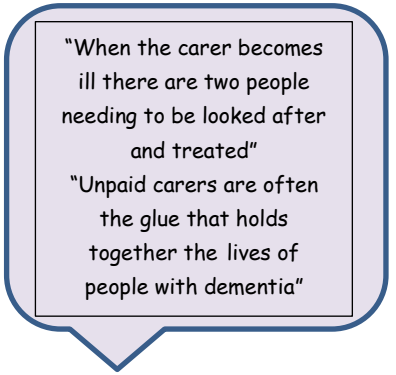
This requires an integrated pathway of support, including between community and hospital provision, building upon the 'Proactive Care' approach, which aims to work with people at every stage of the pathway, with one integrated health and social care multidisciplinary team at the heart of the service[7]. It will be essential that people with a diagnosis of dementia are included on the Dementia Register to ensure regular monitoring and review that considers the health and social care needs of the person with dementia and their carers, identifying any areas requiring additional support before a crisis develops. It

[7] Dr. Katie Armstrong (2012) Proactively caring for the Elderly and those with Complex Need in Sussex

will also be necessary to take an integrated approach to training across wide range of settings. This should build on the Alzheimer's Society Dementia Friends and Champion programme[8] and also have a focus on leadership in dementia provision.

9.4.4 Support for Carers – In order to achieve better outcomes for people with dementia, their families and friends, it is essential that carers are central to the support provided to those with dementia. In line with the Dementia Alliance 'Carers Call for Action'[9] this strategy will ensure that there is:

- recognition of the unique experience of caring for someone with dementia
- carers are recognised as essential partners in care – valuing their knowledge and the support they provide to enable the person with dementia to live well
- have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia.



This will include support for carers and families to help them deal with crises, and the changing nature and severity of people's symptoms, as well as access to psychological therapies. Support of this nature has been demonstrated to help people remain at home significantly longer.

The pathway for people with dementia will also provide clarity about where carers can access support throughout the progression of the relative or friend's condition with dementia. This will align with the services commissioned under the Carers Strategy

It is also essential that carers can access flexible respite that best fits their situation or needs, including for those people from BME groups. To increase the range of respite options, the feasibility of a pilot into extending the use of shared lives for people with dementia, will be considered. This will seek to organise short stays in the homes of local families, as well as 'day shares'.

[8] http://www.dementiafriends.org.uk/
[9] http://www.dementiaaction.org.uk/assets/0000/5695/DAA_The_Carers__Call_to_Action_Nov_7th_2013-1v2.pdf

9.4.5 Meaningful day time activity – WSCC will review the County Council's seven specialist day centres to determine if they reflect current best practice, customer choice and affordability. The Dementia Forums are currently mapping the availability and provision of day time activity, and will seek to work collectively with Commissioners and partners in the community to ensure that there is range of opportunities for people with dementia, across West Sussex, including for people who live in rural areas, younger people and for those from BME groups.

9.4.6 Housing Support – 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, housing advice will also be important for some to help them plan for later life.

Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Living well with dementia Part A	Dementia Friendly Communities	To reduce stigma about dementia and enable more people to live independently for longer	The Dementia Forum Co-ordinator to work with individuals, local businesses, statutory and community based organisations to instigate Dementia Forums across West Sussex and enable them to be self-sustaining and a catalyst for dementia friendly communities	I feel included as a part of society	Roll out of dementia friendly communities across West Sussex with a broad network of support including businesses, transport providers, voluntary and community organisations, health, local government, police and fire

					services.
	Person Centred Approaches	People have maximum control over the decisions that affect their lives and are put at the centre of their care, with access to flexible support	Access to information and advice (see Phase 3 part B). Access to advocacy services to be made available where there is not an appropriate person to represent the individual for: assessment; care planning; support planning; and safeguarding processes, and where there would be substantial difficulty in understanding or communicating information. Front line health and social care staff receive training and support to deliver person centred support with an understanding of dementia. Clearly define who is responsible for supporting people to make advance care plans including for end of life.	I understand so I am able to make decisions. Those around me and looking after me are well supported. I am treated with dignity and respect. I am confident my end of life wishes will be respected.	Access and take up of advocacy. Proportion of health and social care staff trained in person centred approaches and identification and support for people with dementia. Proportion of people with dementia who have End of Life plans.
	Integrated Approaches	For people with dementia to be able to be able to access joined up health and social care and community support throughout the progression of their dementia	Take an integrated, long term condition approach to all core services and management, that takes into account people's physical and mental health needs, with a seamless pathway and network for people with dementia, their families and carers that is adaptable enough to meet every individual's needs. People have an assessment and on-going personalised care plan agreed across health and social care that identifies a named care co-ordinator or point of contact.	I know how I can help myself and who else can help me. I get the treatment and support best for my dementia and life I understand so I am able to make decisions.	Proportion of people that are registered with dementia that have a care plan agreed by health and social care that records a care coordinator point of contact. The proportion of people registered with dementia that have an

			People with dementia receive an annual review (or more often if clinically necessary) that considers health and social care needs and the needs of any carers. People know how to access support and advice at any point of their journey. Those with complex dementia or who develop behaviour that challenges have access to specialist multi-disciplinary support that links with the rest of the pathway and looks to reduce use of anti-psychotic medication.		annual review Rates for prescribing of anti-psychotic medication.
	Support for Carers	Carers of people with dementia are able to access support as needed and feel able to continue with their caring role	All carers including those from BME groups to be able to access information and advice, and training for what to expect and how to respond to challenges that may arise. Carers of those with dementia are offered an assessment and support plan that takes into account their emotional, physical and social care needs. Explore availability and access to psychological therapies Carers are able to access a comprehensive range of flexible respite. Pilot extension to shared lives and shared days scheme to people with dementia.	Those around me and looking after me are well supported.	Proportion of people registered with dementia whose carers have been offered a carers assessment. Availability of psychological support. Take up and satisfaction with shared lives and day share scheme. Proportion of people who when asked stated they

			Review of WSCC directly provided respite provision to ensure that this reflects current best practice, customer choice and affordability.		felt informed about what was available to them.
	Meaningful daytime activity	For people with dementia to have access to a range of affordable day time activity that reflects their interests and needs For people to be supported to maintain and develop their relationships and to be able to contribute to their community	Dementia forums to map provision of day time activities in their area that are accessible to people with dementia including those who live in rural areas, are younger or come from diverse BME groups, and identify gaps. Gaps to be addressed through coordinated action by community based organisations, with pump priming to cover start-up costs of new provision. Review of WSCC directly provided day services provision to ensure this reflects current best practice, customer choice and affordability. Community and residential providers to demonstrate that they enable people with dementia to participate in leisure activities, maintain relationships and contribute to the local community. Link with integration of transport to highlight needs of people with dementia and their carers.	I know what I can do to help myself and who else can help me. I feel included as part of society.	Proportion of people with dementia who express satisfaction about their ability to participate in meaningful daytime activity, maintain relationships or contribute to society
	Housing	For people with dementia to have access to housing that is responsive	Encourage Housing Providers to participate in Dementia Action Alliances and to contribute to the development of communities and	I was diagnosed in a timely way. I know what I can do to help myself and who	Increase in the involvement of housing providers in dementia

		to their needs	environments that are dementia friendly (particularly for new builds and refurbishments). For Housing staff to be trained to identify the symptoms of dementia and know how to encourage people to access support. Additional training to be given to sheltered and extra sheltered housing staff to enable them to support residents who develop dementia, with a view to sustaining more people within their own homes. Access to housing advice at point of diagnosis to enable later life planning	else can help me. I get the treatment and support best for my dementia and life. I feel included as part of society	forums. Roll out of training to housing providers.

9.5 Part B – Living well with Dementia: For people needing more intensive support

"It is important for the carer to understand the individual – they can pick up on changes in behaviour or mood"

9.5.1 Care at Home – this is a key component of enabling people to remain at home for longer. Care workers need to be trained to have better awareness and understanding of dementia, so that they can help to: ensure people are diagnosed and supported earlier; provide person centred, respectful support; and are more equipped to help people in crisis to remain at home or return home after a hospital admission.

9.5.2 Care in Acute Hospitals – In West Sussex during 2012/13, people with dementia accounted for 4404 admissions to acute hospitals. 93% of these were unplanned. The most common reasons for this were urinary tract infections, fractured neck of femur and pneumonia. A national Care Quality Commission (CQC)[10] thematic review showed that in most NHS acute trusts people with dementia stayed significantly longer and were more likely to be readmitted or die in hospital.

[10] Care Quality Commission, Care update, CQC, London

Where ever possible, admissions to hospital for people with dementia should be avoided. Where this is not possible, they should receive compassionate care by skilled staff, in dementia friendly environments. The shared care model of provision (where registered mental health and general nurses work together to provide in-patient care) should be extended across West Sussex hospitals to facilitate faster discharges, reduce readmission rates and increase patient satisfaction.

People showing symptoms of dementia should be identified and assessed. Where dementia is indicated there should be onward referral to the Memory Assessment Service, so that those people, their families and carers receive the same level of support as those whose symptoms were first identified when they were at home.

It is also of vital importance that people with dementia can receive good nourishment and adequate assistance to eat when in hospital and care settings since this provides a valuable opportunity to improve people's health. Consideration will be given to the use of NHS England's recommendation for a Hospital Food CQUIN goal (Commissioning for Quality and Innovation).

9.5.3 Dementia inpatient services –Wherever possible, admission to inpatient facilities should be avoided by a community crisis response and social care support for both the person with dementia and their carer. Where home treatment is not possible, patients should receive compassionate care by skilled staff, in dementia friendly environments.

On admission, integrated health and social care plans for discharge will be defined and agreed between professionals and families at the earliest opportunity to contribute to swift discharges ideally back to the person's own home or to a residential setting where that is not possible.

9.5.4 Care in Residential Homes – This framework will seek to maximise the independence of people with dementia and seek to minimise the need for residential care. Residential care homes will though always be an essential part of the health and social care system. However, 2012/13 CQC[11] research found that those people with dementia living in care homes were more likely to be admitted to hospital for avoidable conditions such as urinary tract infections and dehydration than those

[11] Cited in Department of Health (2013) Dementia A state of the nation report on dementia care and support in England Williams Lea for the Department of Health: London

people living in care homes who did not have that condition. The Alzheimer's Society[12] have also highlighted that there are often low expectations about the standard of care in residential homes. This strategy actively encourages providers to sign up to the Dementia Care & Support Compact[13] instigated by the Prime Minister's Challenge[14] to take action to improve the experience of people with dementia and their families.

WSCC will take steps to enable the market to provide sufficient placements for people with dementia, including for those that require funding from WSCC and for younger people with dementia or from BME groups. It will review directly provided residential provision to ensure such provision is able to meet the needs of local people and maximises the benefit from spend. WSCC also intends to work with providers to implement a Dementia Specification for Residential Care Homes, based upon NICE guidelines to set out clear expectations for delivery and provide a framework for staff training and development. Key to this will be the development of leadership skills required to run excellent dementia services. In reach services will also continue to work with providers to enable them to deliver continuity of support to people within their homes.

Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Living well with dementia Part B	Care at Home	For people with dementia to receive skilled staff support that enables them to remain at home for longer and reduces impact upon families and carers	Commission care through the Care and Support at Home that ensures friendly, respectful capable workers that are trained in identifying early symptoms of dementia and know what next steps to take. People with dementia,	I was diagnosed in a timely way. I get the treatment and support best for my dementia and life. I am treated with dignity and respect.	Proportion of care staff who have received dementia training. Proportion of people with dementia, their families and carers that express satisfaction about the care and support

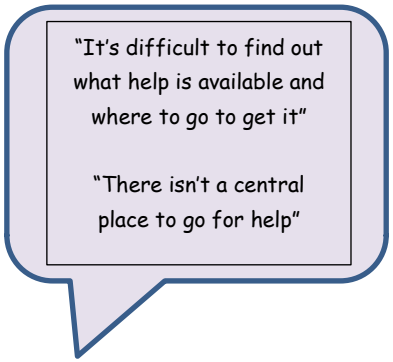
[12] Alzheimer's Society (2013) *Low Expectations: Attitudes on choice, care and community for people with dementia in care homes*
[13] http://www.dementiaaction.org.uk/dementiacompact
[14] Department of Health (2012) *Prime Minister's challenge on dementia, Delivering major improvements in dementia care and research by 2015*

			their families and carers are offered a choice about how they receive their support, including where appropriate to take this as a Direct Payment.		at home that they receive.
	Care in Acute Hospitals	For support to be in place to avoid where ever possible unplanned admissions to hospital. Where hospital admissions are required, for these to be as short as possible, and for people with dementia to receive compassionate care by skilled staff in dementia friendly environments	Increase provision of accessible, quality contingency plans to all people registered with dementia. Explore options of extending urgent community provision to be 24/7 to increase admission avoidance. Collate further evidence on the benefits of shared care model, with a view to extending this across West Sussex to facilitate faster discharges, reduce readmission rates and increase patient satisfaction. Consider steps required to enable hospital environments to be dementia friendly Where dementia is indicated there should be onward referral to the Memory Assessment	I get the treatment and support, best for my dementia and life. I am treated with dignity and respect I was diagnosed in a timely way.	Reduce length of stays for people with dementia. Demonstrate improvements in patient and carer experience through satisfaction measures. Demonstrate improvements in the environment through audits in line with recognised dementia friendly environment models, such as that described by Stirling University and the Kings Fund.

			Service Consider use of NHS England's Hospital Food CQUIN goal		
	Dementia In-patient Services	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.	Scope the number of inpatient beds required in West Sussex, and alternative options such as enhanced care/nursing home places for patients in need of intensive support. Explore opportunities to speed up on-going funding routes such as continuing healthcare to ensure that patients are not delayed unnecessarily in hospital.	I get the best treatment in the most appropriate place at the right time. I am treated with dignity and respect. I know that my needs on leaving the hospital will be explored by professionals and a plan for my discharge agreed with my family and I.	Monitor the number of people admitted to dementia inpatient beds. Monitor delayed transfers of care from inpatient beds.
	Care in residential Homes	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 communties	Staff in all care homes to be able to identify the symptoms of dementia and know how to access support. Implement the Dementia specification for residential care homes. Encourage dementia care homes to become active members of local dementia forums. Encourage care homes to sign the Dementia Care	I get the treatment and support, best for my life dementia and my life. I am treated with dignity and respect. I am confident that my end of life wishes will be respected. I am diagnosed in a timely way.	The successful implementation of the dementia specification. Proportion of dementia care homes that participate in dementia forums. The proportion of care homes that sign the Dementia Care and Support Compact.

			and Support Compact Review of WSCC directly provided provision of residential care to ensure that it meets best practice, affordability and customer choice. Facilitate mechanisms for supporting excellent dementia service leadership.		A reduction in the numbers of avoidable admissions to hospital from care homes.

9.6 Phase 4 – Getting the right help at the right time:



9.6.1 Information and Advice - In all the discussions that were had to develop this framework, local people, voluntary agencies and staff consistently highlighted of the importance of access to information and advice that is given at the right time in the right way. It is essential that people know who to contact for advice and information and that it is shared in a way that is helpful to people with dementia, their families and carers and to those who are deaf or hard of hearing, have a visual impairment or whose first language is not English. Central to this will be a joined up pathway so people know how to access support.

9.6.2 Help in times of crisis - It is also essential that there are robust and integrated services that are equipped to provide rapid support to people in crisis, regardless of the cause, be it due to a deterioration in their physical health, their mental health, a change in the social circumstances, or the needs of their carer.

The promotion of advanced decisions and contingency planning for all people with dementia will help to manage unexpected deterioration. These need to be an integral part of the pathway for people with dementia. People need to know how to access timely information, and that families and carers know about common changes; what to do to avoid crisis; who to contact; and the care and support options available.

The use of technology to support independence also needs to be promoted. There is now a variety of assistive technology that can help people with dementia to maintain their independence for longer. Research also demonstrates that this can reduce anxiety for families and carers.

Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Getting the right help at the right time	Information and advice	People with dementia, their families and carers are aware of how to access information and advice throughout the progression of their dementia and have a single point of information for local dementia care and services	A single agreed first point of contact for people with dementia, their families and carers. Develop a dementia mini site within West Sussex Connect to Support with information and advice on goods and services, places of support, and information on disease progression. Include printable leaflets for people who do not have access to the internet. The site will also seek to highlight those providers who identify themselves as dementia friendly.	I know what I can do to help myself and who else can help me	Development of a consistent and clear route to information and advice that supports people, families and carers throughout the progress of their dementia, that people know how to access. People with dementia, their families and carers, express satisfaction with that provision and accessibility.
	Help in times of crisis	People with dementia, their families and carers are	All people registered with dementia are supported to complete a contingency plan that	I know what I can do to help myself and who else can help me.	Proportion of people registered with dementia that have an accessible contingency

		supported to plan for crisis and receive robust support should a crisis occur regardless of the cause, that helps to maintain independence	seeks to support people to remain in their own homes where possible and that these are accessible to staff responding to crisis such as paramedics. People are supported by integrated services that are equipped to provide rapid support to people in crisis, including out of usual office hours. There is consistent provision of rapid response services throughout West Sussex.	I get the treatment and support best for my dementia and my life. I am confident my wishes will be respected.	plan that supports independence. Reduction in avoidable admissions to hospital and residential placements.
	Use of Technology	Technology helps people with dementia to maintain their independence and helps to reduce carer anxiety	Access to 13 week free trial of assistive technology products. Explore new opportunities to use assistive technology to maintain independence.	I know what I can do to help myself and who else can help me. I get the treatment and support best for my dementia and life.	Increase take up of telecare products for those with dementia and their families and carers.

9.7 Phase 5 - Nearing the end of life including care in the last days of life

9.7.1 Recognising the end of life phase – It is essential that family members, carers and professionals recognise and understand when the person with dementia is nearing the end of their life. Ensuring that the person with dementia's Advance

Care Plan is reviewed regularly will give clinicians the confidence to arrange care in the preferred place. Spiritual and cultural needs should be taken into account at all phases of the pathway.

The Gold Standards Framework and End of Life Register will be used as best practice to support the person with dementia to a 'good death'.

CCGs and WSCC will continue the rollout and promotion of the Sussex Integrated End of life and Dementia pathway – this will include training for professionals and promotion of Advance Care Planning at all phases of the pathway as appropriate.

Coastal West Sussex CCG has undertaken a stocktake to benchmark against national and local End of Life Care priorities, which will inform the development of a long term strategy with the aim of addressing identified inequalities, raising the profile of End of Life Care and ensuring efficient and appropriate use of resources to improve experience at end of life.

The two CCGs in the north of West Sussex continue to focus on delivery of the Electronic Palliative Care Co-ordination System (EPaCCS) which will ensure joined-up delivery of care of patients at end of life by allowing health professionals to contribute to, or read, documents such as advance care plans and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

Horsham and Mid Sussex CCG has also extended its local Quality Premium around increasing the number of patients who die in their preferred place.

The emotional wellbeing of carers is key at this phase, and carers will be supported throughout the end of life phase and bereavement.

Phase	Area	Outcome by 2019	Commissioning Intention	What this will mean for people with dementia, their families and carers	How will success be measured
Nearing the End of Life	Information and advice	Carers understand the	The advance care plans for people with dementia	I am confident that my end of life wishes will be	Proportion of people who have

		end of life phase and are supported through it by professionals. People with dementia will be able to have a 'good death' according to the wishes of their advance care plan.	will be shared as appropriate with professionals managing their care, so that the end of life stage is planned for, recognised and the wishes within the advance care plan can be actioned. The Sussex Integrated Dementia and End of Life pathway will continue to be promoted and embedded in good practice across West Sussex. All residential care homes to be encouraged to have end of life discussions with the people living with dementia and or their family members at point of admission.	respected. I can expect a good death. I am treated with dignity and respect.	an advance care plan. Proportion of people who are on a palliative care register and receiving regular support.
	Training	Professionals caring for people with dementia understand the end of life stage and how to manage and care for the	Professionals who work with people with dementia will receive training on the importance of advance care planning, supporting the person with dementia and the carer throughout	I know that the people looking after me understand my wishes and will treat me with dignity and respect.	Baseline then monitor the number of professionals who feel confident to support the person with dementia through

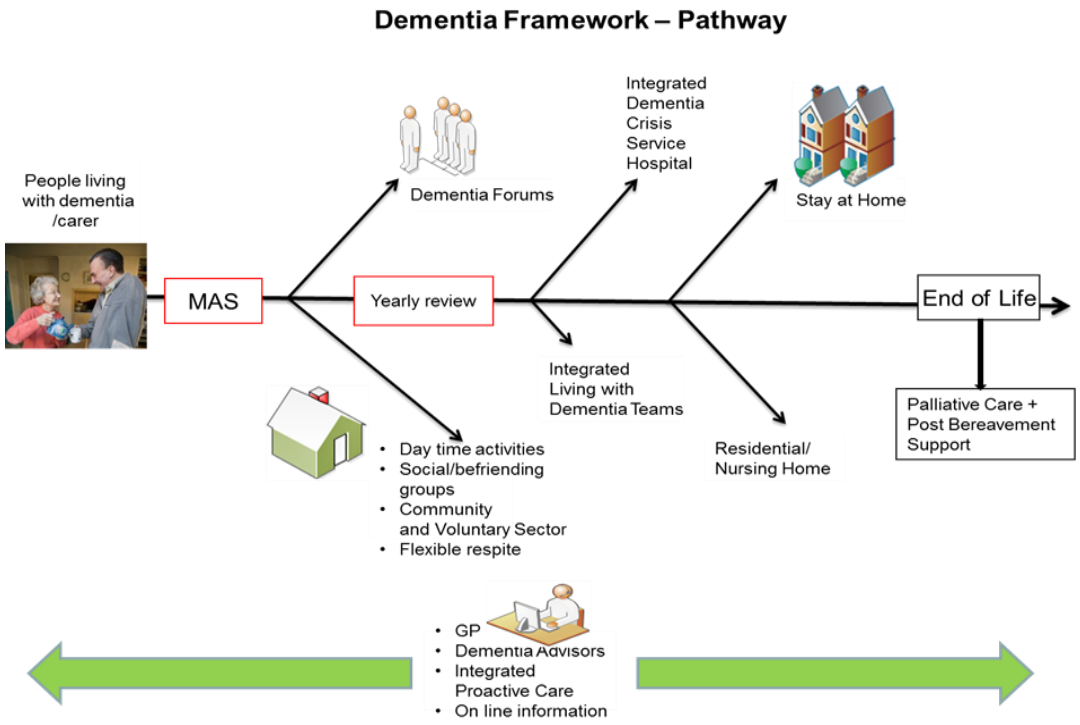
		person with dementia and their family.	the end of life stage, that also takes into account their spiritual and cultural needs		the end of life stage.
	Bereavement support	Carers are supported during and after the end of life stage and are offered post bereavement support.	The pathway and availability of bereavement and post bereavement support will be mapped and options for the best way to offer support to carers will be explored.	I am confident that I will be supported during and after the death of my loved one.	Proportion of carers who receive specific support at bereavement and post bereavement.

9.8 Research

The G8 Dementia Summit has pledged to find a cure or disease modifying therapy for dementia by 2025[15]. To this end, the government has committed to encouraging people to contribute to research. In West Sussex, local people need to know how they can do this, should they wish to participate. West Sussex Public Health is also committed to contributing to the evidence base for effective interventions, for example, through contributing to robust evaluation of shared care wards.

[15] Department of Health (2013) Policy Paper *G8 Dementia Summit Declaration*

10.0 Care Pathway description and diagrams



- People who are suspected of having dementia will have access to Memory Assessment Services proportionate to their needs.
- On diagnosis, people with dementia and their carers will be offered support and encouragement to maintain their social contacts or access meaningful day time activity.
- Dementia Forums will work to develop dementia friendly communities and act as a point of contact for people with dementia to influence future provision.
- All people registered with dementia and their carers will have access to dementia advisors as well as on line information throughout.
- All people registered with dementia will be offered holistic annual reviews.
- People with complex needs relating to their dementia will receive assistance via integrated health and social care teams such as the living well with dementia teams and crisis support.
- Proactive Care will support an integrated view of all the person's long term conditions
- People will be supported to maintain their independence for as long as possible, if they require residential care, there will be a sufficiency of quality provision
- People with dementia, their carers and families will be supported with end of life planning

11.0 How we will get there

An implementation and investment plan (with more detailed evaluating measures) will be developed with the aim of ensuring that all the priorities identified within the Framework are achieved. It is anticipated that in addition to on-going funding from health and social care for people with Dementia, further transformation funds may become available to support the implementation of the Framework, for example from the NHS for Social Care Fund or the Better Care Fund. This is not new money; instead it is to reinvestment of existing funds to support a shift away from traditional acute settings to community based integrated provision. The measures for the Dementia Framework will align with the Better Care Fund measures, for example around estimated rate of diagnosis.

Despite this additional funding for Dementia provision, overall it is likely that there will be fewer resources within health and social care. This combined with escalating demand for support and services will mean there will be significant challenges for achieving our priorities. Therefore, at the heart of this, there will need to be a collaborative approach across health, social care, community, voluntary and private providers, in conjunction with local people. The Dementia Forums that are currently being developed across West Sussex will be integral to its implementation, as will the Joint Implementation Group comprising of health and social care commissioners, providers and voluntary sector organisations. Not all of the priorities can be achieved at once and a phased approach will be taken to its implementation, with measures and points of review to ensure the steps being taken are having the expected impact.

This is a word cloud from the survey returns. The size of the words reflects how frequently they were used.