





In partnership with:

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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Within West Sussex, we want people to be supported to maintain their independence for as long as possible.

In this document we use terms that may require a definition

Advance Care Plan
A plan for future and end of life care.

Assistive technology

Devices to help with everyday living.

Commissioning

The process of planning, agreeing and monitoring services needed by the people who live in the area and making sure they are available.

Dementia

An illness that affects someone's thinking and memory.

Memory Assessment Services (MAS)

Somewhere people can go to find out if they have dementia and which can provide help on living with dementia. A person's GP can refer them to this service if appropriate.

Mild cognitive impairment

A condition involving problems with memory and thinking skills which are not severe enough to interfere with a person's daily life.

Vascular dementia

A type of dementia caused by problems in the supply of blood to the brain.





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 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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Introduction

This document is a summary of the full Dementia Framework West Sussex 2014-2019.

The aim of this framework is to set out the main areas for 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 the three clinical commissioning groups (CCG's) in West Sussex: NHS Coastal West Sussex CCG, NHS Crawley CCG, NHS Horsham and Mid Sussex CCG. It lets local people and organisations know about services being provided now and how they will change or develop over the next five years. It sets out goals to help people live well with dementia.

The framework is based upon the views of local people with dementia, their families and carers, care providers, and health and social care staff and sits within national and local policy. Information has also been taken from national and local guidance including the National Dementia Strategy; the West Sussex Needs Assessment for people with Dementia; and a review of the things that help support people with dementia remain independent.

The framework sets out how organisations and people across West Sussex can work together to achieve a shared vision, where people can say:

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 feel included as part of society.

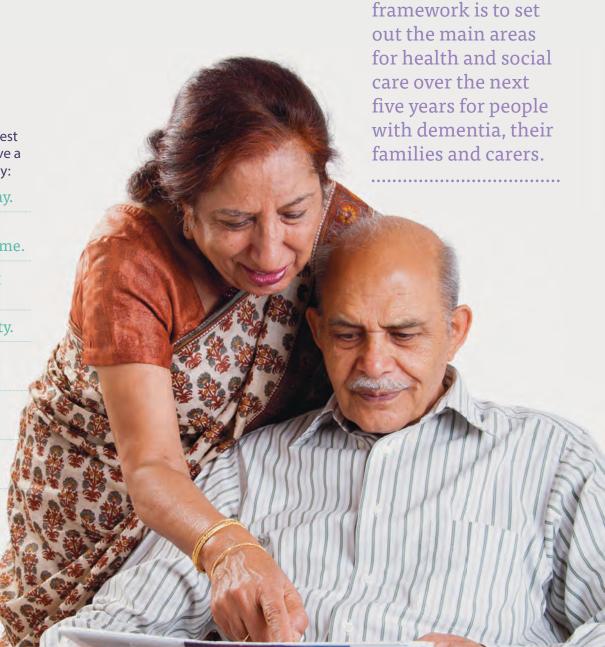
I understand so I am able to make decisions.

I get the right treatment and support.

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 take part in research



The aim of this

What have we achieved already?

Organisations across West Sussex have worked together and achieved:

Timely diagnosis - through a memory assessment service (MAS) which includes assessment, diagnosis, on going support from dementia advisers, medication reviews and training for carers.

Integrated dementia crisis teams - providing a health and social care response when things go wrong including 72hrs of intensive support and up to six weeks of care and support at home and respite.

The Care Home in Reach service - working with care and nursing homes across West Sussex to improve the care and support for residents.

Dementia action alliances - aimed at encouraging and supporting communities and organisations to take practical actions to enable people to live well with dementia.

Assistive technology - people with dementia in West Sussex can access community alarms and linked sensors. There is also an offer to carers for assistive technologies such as bed sensors and automated reminders.

Support for carers - Carers Support West Sussex has been providing a consistent offer of support, information and guidance to all carers. This has provided a gateway service to all other carers support services within the county, such as carer breaks and more specialist services.

How did we develop the framework?

It was important to engage with West Sussex people who have dementia, their families and carers, as well as staff and organisations involved in providing services. We used a variety of different methods to help us develop the framework including focus groups, personal journeys, surveys, stakeholder events as well as new local and national research.

We also looked at the West Sussex Carers Survey. It highlighted that people caring for someone with dementia were more likely to report worries about their safety, a lack of emotional support and social contact and finding it more difficult to do things they enjoyed 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.

Priority areas

The priorities are set around seven themes. The full length framework gives more information about the types of support we think need to be developed.

Prevention

- People are encouraged to lead healthy lives to help prevent vascular dementia.
- Greater dementia awareness across the general public in West Sussex including people from diverse ethnic backgrounds. This will help to reduce stigma and encourage people worried about their memory to seek a diagnosis.

Recognising there is a problem

• Improvement in the time it takes for people to get a diagnosis by working with staff from health, social care, community and housing settings to identify symptoms and know what steps to take to support people to get a diagnosis.

Discovering the condition is dementia

- All groups of people are able to get an early diagnosis and they and their families and carers feel supported after they have been diagnosed.
- People with alcohol related dementia know where to go for support.
- There is support for people who were diagnosed before the Memory Assessment Service (MAS) started.
- Reviews for people diagnosed with mild cognitive impairment.

Carers are supported in their roles and have a range of flexible respite options available to them.



Living well with dementia

- Dementia friendly communities are developed.
- Health and social care professionals work together to support the person with dementia to be involved with decisions about their care.
- Carers are supported in their roles and have a range of flexible respite options available to them.
- There is a range of meaningful activities that also meets the needs of younger people with dementia, people living in rural areas and people from diverse ethnic backgrounds.
- Housing providers receive help to be "dementia friendly".

For people with greater support needs:

- Care at home is available with skilled staff.
- Care in hospitals wherever possible is avoided, but where this is required, people with dementia stay for as short a time as possible and steps are taken to help people receive good care by skilled staff in dementia friendly settings.
- There are enough quality residential homes for those who can no longer be supported at home.



Getting the right help at the right time

- People with dementia, their families and carers are able to get information that is right for them at the right time.
- A single dementia website linked to West Sussex Connect to Support, with leaflets for those who cannot access the internet. (www.westsussexconnecttosupport.org/ dementia)
- All people registered with dementia are supported to complete a plan in case things change in the future that seeks to support people to stay in their own homes.
- People are able to use technology that supports them to stay at home for longer.
- There is enough support across the county for when things go wrong.

Nearing the end of life

 Advance Care Plans are used more, and staff are trained to understand the importance of this kind of care planning and how to support people with dementia and their carers through the end stage of life.

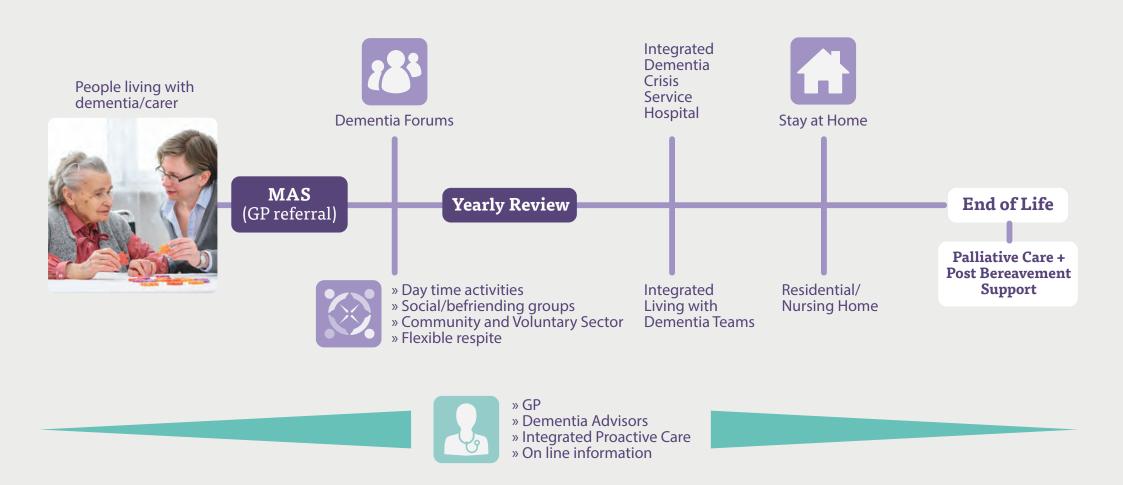
Support to engage with research

 Local people know how to take part in research if they want to.

People with dementia, their families and carers are able to get information that is right for them at the right time.

The dementia care pathway

This is a pictorial overview of the pathway, the full length framework gives more complete information.



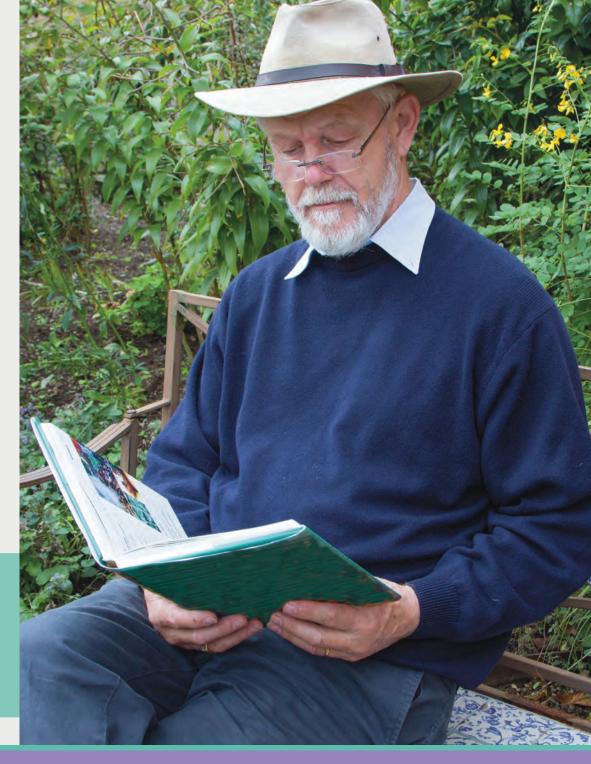
How we will get there

Health, social care, community, voluntary and private providers will need to work with each other and with local people to build on the good practice already in place in West Sussex. Not all the priorities can be achieved at once, we will be developing a plan that has a number of stages that will take place over five years. The plan will have a set of measures to ensure we achieve the goals we have set out in the framework.

To view the full framework please visit the Dementia area of the West Sussex Connect to Support website **www.westsussexconnecttosupport.org**

If you have concerns about dementia please either contact your local GP or Adults' CarePoint for social care enquiries – phone **01243 642121** or email **socialcare@westsussex.gov.uk**

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