High Weald Lewes and Havens Clinical Commissioning Group (HWLH CCG) is the NHS commissioning organisation responsible for high quality and safe services which meet the health needs of the local population. We want to review the current provision of local services to ensure that every pound we spend achieves the best possible outcomes for people living with dementia and their family/carers.

HWLH CCG is a GP-led body that plans and buys a wide range of health services on behalf of people in the High Weald Lewes Havens area.

We bring together 125 GPs, working in 20 practices, who look after more than 164,000 people who live in the area (93,000 in High Weald, 71,000 in Lewes Havens).

HWLH CCG’s population profile is older than the average for England and Wales; with projections showing that the proportion of older people will continue to increase - most significantly in those aged 85 and over.
Local priorities for services

We are committed to commissioning a range of high quality dementia services which improve the lives of people living with dementia and their family/carers in High Weald, Lewes and the Havens. We will do this by continuing to focus on the priorities of:

- Public and professional awareness and understanding of dementia;
- Good-quality early diagnosis, treatment and intervention for all;
- High quality information and easy access to care, support and advice following diagnosis;
- Developing services which work together in a seamless way, to meet people’s individual needs and preferences, as close to home as possible;
- Supporting carers;
- Improved quality of care for people with dementia in general hospitals;
- Developing an enabling culture in existing services, which supports people with dementia to recover from illness or injury and to return home (if this is their preference);
- Developing support services, (including Telecare), which enable people to live as independently as possible, for as long as possible;
- Ensuring that anyone working with people with dementia is skilled and competent in delivering care and support, in a compassionate way;
- Improving end of life care and ensuring that people with dementia and their family/carers have discussions early enough in their journey to support preferred priorities of care; and
- Ensuring that decisions about future services are clinically-led and informed by patient and public experience.
Clinical Chair and Clinical Lead
Introduction

Clinical Chair – Dr Elizabeth Gill

Elizabeth qualified from St Bartholomew's Medical School in 1996. She worked in a variety of hospital jobs at Barts, the Royal London and Homerton, including as a staff grade in the A&E at the Royal London as part of the trauma team.

Elizabeth then moved to Brighton to pursue her GP career. Elizabeth has worked at Buxted surgery since 2003 where she completed her GP training, gaining her MRCGP. She became a partner and GP trainer in May 2010.

Elizabeth became Practice-Based Commissioning Chair for High Weald in October 2010, then High Weald CCG Chair, and was elected as Chair of HWLH CCG upon its merger in May 2012. Elizabeth successfully passed the Chair Assessment unconditionally in September 2012.

Dr Elizabeth Gill, local GP and Chair of High Weald Lewes Havens CCG said:

“Ensuring local patients with dementia have access to safe and high quality services is a key priority for our CCG and we want to ensure that the services patients receive are fit for purpose in the future.

This is why we have made the review of dementia services a priority. We know that we can do so much more for patients and their families living with the condition and continuing to do the same is not good enough. We will listen to patients, carers, the public, stakeholders and our providers in order to understand what we can improve and then work together, to create a new model of care for the future, which will improve the quality of life and outcomes, of people affected by dementia.”
Clinical Lead – Dr Emma Costello

Emma qualified from St. Georges Hospital Medical School, London in 2007. She worked and trained in hospitals in London, Tunbridge Wells and Eastbourne.

Emma is currently a sessional GP covering High Weald Lewes Haves, East Sussex region. Emma is the clinical lead for Dementia focussing on developing patient and carer services.

Brighton and Sussex Medical Schools have formed a Dementia Fellowship: ‘Creating Better Dementia Care’. The Fellowship runs a training programme which trains and develops GPs, practice nurses and community staff to help them create better dementia care in practices and the community. Recently, Emma became a Dementia Fellow, networking with professionals with a passion for excellent dementia care in the community.
Structure

1. About Dementia
   What is Dementia?
   National Dementia Strategy
   The Size of the Challenge
   Economic Challenge
   Impact of Dementia

2. Phases of the Dementia Journey
   The Current Dementia Pathway in High Weald Lewes Havens

3. A Case for Change
   A Case for Change Introduction
   A Case for Change Structure
   ◆ Clinicians’ Feedback
   ◆ Patients’ and Carers’ Feedback
   ◆ Patient Participation Group (PPG) Feedback
   ◆ Carers’ Experience
   Engagement Summary
   Current Dementia Services Model

4. The Future - An emerging model of care
   Future Plans
   Principles of the New Model
   What does the Golden Ticket give people?
   What is the intended benefit?

5. What happens next?
   What Happens Next?
   Supporting Work Projects

6. Abbreviations
What is Dementia?

The word dementia describes 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. It is not a natural part of getting old. Dementia is progressive, which means the symptoms will gradually get worse.

Source: Dementia Forward

There are many different types of dementia; although some are far more common than others. They are often named according to the condition that has caused the dementia.
National Dementia Strategy

In 2009, the Department of Health launched the first ever National Dementia Strategy for England. Alzheimer's Society worked closely with the government to develop the Strategy.

The Strategy is the government's plan which explains what needs to happen to radically transform the quality of life for people with dementia and their carers in the future.

The Dementia Strategy sets out 17 recommendations that the government wants the NHS, local authorities and others to undertake to improve dementia care services. The recommendations are focused on three key themes of:

- Raising awareness and understanding;
- Early diagnosis and support; and
- Living well with dementia.

Since the launch of the National Dementia Strategy in 2009, significant investment and progress has been made in the development of local services across East Sussex. However, now 5 years on from the Strategy, the evidence base for good practice has evolved and new models of care are emerging. Learning from the evidence base, the National Institute for Health and Care Excellence (NICE), now sets out ten principles to commissioning dementia services.

Across East Sussex, some of these principles exist within the established dementia pathway, but to what extent and how well services are working for people with dementia and their family carers is more ambiguous.

The time is ripe to reflect on our implementation of its key recommendations and to ask important questions, such as:

- Can we be assured that HWLH CCG is encouraging people to seek help early for problems with memory, and that they are receiving a prompt and competent specialist assessment, followed by an accurate diagnosis, which is sensitively given?
- Has appropriate care and support been given at the right place and right time in the person and family’s journey with dementia?
- Have people received coordinated care, with seamless contact between services that help people with dementia and their loved ones to live well with dementia?
The Size of the Challenge

Prevalence of Dementia

The prevalence of dementia increases with age, and is estimated to be approximately 20% at 80 years of age. Given the relatively high numbers of frail elderly in the CCG area, the management of Dementia is a growing concern for HWLH CCG. The HWLH area is currently performing below the national average for diagnosis rates but, more importantly, there is a large number of people living with the condition, including their family/carers, who do not have a diagnosis. Those people, and their family/carers, therefore do not have access to treatment, information and support, to help them live more independently and prevent them from getting into difficulty. This is an unacceptable picture and one that will continue to get worse as the population ages, if we don’t review the local approach.

In HWLH, we know that in 2013, there were 901 people living with a diagnosis of dementia (eastsussexjsna.org.uk), which represents only 41.40% of the number of people; we would expect to be living with the condition in the locality.

Source: National Audit Office analysis of QOF data presented in the 2009 Alzheimer’s Society report Dementia: What Every Commissioner Needs to Know. An index has been created reflecting the current and future (2021) prevalence of dementia and the dementia diagnosis gap in each SHA. The higher the index, the greater the challenge for that SHA to reduce the diagnosis gap in their region.
Economic Challenge

Dementia is one of the main causes of disability later in life. Economically, it is also one of the biggest financial challenges of the health and social care system; costing more than cancer, heart disease and stroke combined.

Source: Alzheimer’s Society 2013, alzheimers.org.uk

Since 2007, the total cost of dementia has continued to rise.

The Dementia UK report estimated that the total annual cost per person with dementia in different settings in 2007 was as follows:

- People in the community with mild dementia - £14,540
- People in the community with moderate dementia - £20,355
- People in the community with severe dementia - £28,527
- People in care homes - £31,263.

The overall costs of dementia in the UK were calculated using new data on the prevalence of dementia from Dementia UK, together with other data. Costs included those provided by formal care agencies, as well as the financial value of unpaid informal care provided by family and friends. Costs were not available for the 2% of people with dementia under the age of 65.

Over a third of the total cost (36%) was due to informal care input by family members and other unpaid carers. Not included in this amount is the estimated £690 million in lost income...
for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer.

Accommodation accounted for 41% of the total cost. The greatest proportion of direct costs of dementia care is associated with institutional support in care homes. This is often provided at a crisis point, is always costly and often precipitated by a lack of effective support.
Impact of Dementia

Dementia can be a devastating condition for both those who develop the illness and the families who care for them. It is also very common, and will touch the lives of most of us in some way. We probably all know someone, be it a relative, friend or neighbour, whose life has changed when they developed the condition.

All types of dementia are progressive. The person's ability to remember, understand, communicate and reason gradually declines. Each person is unique and experiences dementia in their own way, therefore the rate of which dementia progresses depends on the individual.

In a third of cases, dementia is associated with other psychiatric symptoms, such as depressive disorder, adjustment disorder, generalised anxiety disorder and alcohol-related problems. A major priority will therefore be to prepare the Primary Care workforce to detect Dementia at an early stage and prepare a package of care that manages their condition and associated co-morbidity, and maintains as high a quality of life for patients for as long as possible.
Phases of the Dementia Journey

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>When memory problems have prompted me and/or my carer or family to approach my GP with concerns</th>
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<tbody>
<tr>
<td>Phase 2</td>
<td>Learning that the condition is dementia</td>
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<tr>
<td>Phase 3</td>
<td>Learning more about the disease, options for treatment and care, self-management and support for me and my carer or family.</td>
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<tr>
<td>Phase 4</td>
<td>Getting the right help at the right time to live well with dementia, prevent crises and manage together</td>
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<td>Phase 5</td>
<td>Getting help if it is not possible to stay at home, or if hospital care is needed</td>
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<td>Phase 6</td>
<td>Receiving care, compassion and support at the end of life.</td>
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The way people experience dementia depends on many factors, including physical make-up, emotional resilience and the support available to them. Viewing dementia as a series of stages can be a useful way to understand the illness, but it is important to realize that this only provides a rough guide to the progress of the condition.
The Current Dementia Model

**PATIENT NEEDS/PRESENTATION**

- Worried about Memory
- Worsening problems, Dementia – moderate/severe
- Can't navigate service options
- Can't undertake all tasks of daily living
- Worsening problems, Dementia – moderate/severe
- Has Behavioural and Psychological Symptoms of Dementia (BPSD)
- At risk of harm to self or other/MH Act
- Co-morbidity dementia/ physical ill health

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**GP Consultation**
- Cognitive screening
- Watchful waiting
- Pre-(MAS) referral to Dementia Advisors
- Referral to Memory Assessment Services

**Memory Assessment Services (MAS)**
- Diagnosis
- Prescribing and titration
- Referral to Dementia Advisors
- Referral to ASC and/ or SPFT (if appropriate/ necessary)
- Management plan including actions taken and to be taken (contingent)
- Discharge to GP

**Dementia Advisors (Alzheimer's Society)**
- Information, advice and support
- Contact for helping navigate service options in future
- Referral to dementia support services

**Dementia Support Services**
- Community based programmes / education e.g. cognitive stimulation

**GP Consultation**
- Resources to MAS management plan
- Referral options – see below (bold)

**Adult Social Care (ASC)**
- Patient assessment of social care needs
- Carer assessment, as required
- Home care, and support
- Care home admission, as required

**Care Home In-reach**
- SPFT specialist dementia team
- Psychiatric, nursing and occupational therapy input
- Individual patient level
- Care home staff training programme

**Sussex Partnerships Trust – Specialist Older Adults Team**
- Assessment and treatment, and diagnosis as necessary
- Complex case management
- Extended hours team, evenings and weekends
- Referral to ASC, as appropriate
- Discharge planning
- Admission to dementia in-patient beds, as necessary

**Dementia In-patients beds**
- Assessment and treatment, and diagnosis as necessary – place of safety
- Referral to ASC, as appropriate
- Discharge planning including to care home, as necessary

**Practice-based Multi-disciplinary Team- Specialist Dementia Participation**
- Identification of high risk patients in community
- Specialist dementia participation and / or care co-ordination
- SPFT facilitated access to appropriate dementia services on care pathway

**Acute Hospital – Older People’s Psychiatric Liaison Team**
- Specialist dementia assessment and management advice service (not diagnosis)
- Support in discharge planning / liaison with community services

**Advanced Care Planning (ACP) & End of Life Care (EoLC)**
The activities apply to all stages of the pathway. Opportunities to sensitively discuss ACP & EoLC should be sought at any time. East Sussex is a signatory to the Sussex Integrated End of Life Care Pathway.
A Case for Change
A Case for Change

Introduction

As clinical commissioners, we work closely with our GP member practices, local patients and the public, neighbouring CCGs, provider organisations and other strategic partners (such as East Sussex County Council) to develop our plans and strategies for how we will work to improve the health of local people.

What we did

Across East Sussex, we wanted to know how well services were working for health professionals, people living with dementia and their family carers. That is why we went out and spoke with people who have experienced the dementia services on offer in HWLH.

Engaging with GP member practices

A patient’s GP is often their first point of contact if they have any concerns about their memory. With dementia, the GP plays a central role in: diagnosis; accessing the right support and treatments; and ensuring patients receive support to live well with dementia and plan for their future. For these reasons, it is important to hear GPs’ experiences. Some important questions need to be asked in regards to:

- **Prevention** - e.g. Are GPs pro-active? Do they feel they have the tools to support patients with concerns about their memory?
- **Recognising problems early** - Do GPs know what to do if they suspect early signs of dementia?
- **Learning it’s dementia** - What does this mean for the patient and what do GPs feel their role is once the patient receives a dementia diagnosis?
- **Dementia Advisers** - Do GPs know who their local Dementia Advisers are? Do they understand what they do and how they can support the person living with dementia and their carer?
- **Living with dementia** - Do GPs feel confident to be able to offer support and guidance to a person living with dementia and their carer? Do they know where the patient is on their dementia journey?
- **Advanced Care Planning (ACP)** - Do GPs engage with ACP? Do they have time to complete ACPs and keep them up to date? Are they the most appropriate person to do this with the patient?
- **Support for Carers** - Do GPs identify the carer’s needs when a diagnosis is given? Are GPs able to support the carer(s) independently of the person living with dementia? Are they able to communicate with carers about the health of both the person living with dementia and the carer?
Engaging with local patients and the public

The CCG buys and plans health services on behalf of the local population, and we want to make sure that people with dementia and their family and carers have access to a range of high quality services which meets the needs of our population. That is, do patients have access to the right care, at the right time and in the right place? By having discussions with those who use our local dementia services we are able to better understand their needs, experiences, concerns and ideas for improvement.

We recognise that a dementia diagnosis does not just affect the person living with the diagnosis; it also affects those around them (even if they do not think of themselves as carers). For this reason, we reviewed patient feedback received by the Memory Assessment Service (MAS), Dementia Adviser (DA) service, Memory Support Service (MSS) and the Care Home In-Reach (CHiR) service:

- **MAS**- Were you given a timely diagnosis? How was the diagnosis given?
- **Support after diagnosis**- What support were you offered? What support did you find most useful? How easy was it for you to access available support?
- **DA services**- Were you referred? If so when? Do you use the DA service? What are your experiences with this service?
- **MSS**- Were you referred? Do you use the MSS? What are your experiences with this service?
- **CHiR**- How have they helped you and your loved one?

For all of the above topics we considered the following questions:

- What was good about these services?
- What if anything could improve this service? and
- What would have made your experiences/future experiences with dementia services better?

We also gathered feedback about patient experiences by visiting Patient Participation Groups (PPGs) within the locality. By talking to PPG members we could better understand what those in the community thought about the dementia services, including:

- What the barriers are to diagnosis in the community;
- Concerns about living with dementia;
- Experiences about caring for someone with dementia; and
- Views on dementia in care homes.
A Case for Change Structure

1. Clinicians’ Feedback
   - Introducing our experts
   - Prevention
   - Recognising problems early
   - Learning it’s dementia
   - Dementia Advisers (DAs) and Support Services
   - Living with Dementia
   - Advanced Care Planning (ACP)
   - Support for carers

2. Patients’ and Carers’ Experience
   - Memory Assessment Services (MAS)
   - Support after diagnosis
   - Dementia Advisers (DAs)
   - Memory Support Services (MSS)
   - Care Home in-Reach (CHiR)

3. Patient Participation Group (PPG) Feedback
   - The diagnosis
   - Living with dementia
   - Caring for someone with dementia
   - Dementia in care homes

4. Carers’ Experience
Clinicians’ Feedback

Diagnosing dementia early means you can get the treatment and support you need to live well. Help and support is available. You don’t have to deal with dementia alone.

Talk to your GP
Introducing our experts

Clinical Engagement meetings have included members from the following practices:

- Meads Medical Centre
- Rowe Avenue Surgery
- Foxhill Surgery
- Groombridge and Hartfield Medical Group
- Beacon Surgery
- Belmont Surgery
- Buxted Medical Centre
- River Lodge Surgery
- Quayside Surgery
- Bird In-Eye Surgery

Informal Meetings have been had with:

- Healthwatch
- Memory Assessment Service (MAS) Lead
- Alzheimer’s Society
- Living Well Dementia Teams
- NHS England
- East Sussex Healthcare NHS Trust
# Prevention – What GPs said

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<thead>
<tr>
<th>Challenges</th>
<th>What Can Help</th>
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<tr>
<td>• When a patient with Mild Cognitive Impairment (MCI) is referred back to GP, GPs don’t know what to do with the patient. As the patient does not fall under any support service/teams, they have no one to contact and don’t go anywhere.</td>
<td>• Managing comorbidities and complex cases. The Practice will start doing telephone assessments. This service should provide more appropriate treatment options by signposting people to the right place.</td>
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<td>• Many GPs admitted not actively seeking out patients unless they were vulnerable. Reasons for this were: not everyone wants mental health checks; encouraging at risk people to talk about their memory may be inappropriate; there is no support to offer them after diagnosis and they are not convinced that there is enough evidence to suggest that an early diagnosis leads to any improved treatment or solutions (ethical issues).</td>
<td>• Early interventions and signposting need to be utilised.</td>
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<td>• The system is re-active. Dementia Advisers (DAs) are not helpful in this respect.</td>
<td>• More people should be allowed to attend community clubs regardless of having a diagnosis.</td>
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<td>• GPs can be reluctant to diagnose more patients as it is time-consuming and added responsibility. It will add ‘x’ amount of time for doing: reviews, communication, diagnosis, counselling and after care.</td>
<td>• The system needs to be more pro-active, whereas it is currently re-active. There needs to be services who are able to provide a preventative service, that is to say, to prevent decline.</td>
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<td>• There needs to be more focus on known available treatment for MCI and dementia.</td>
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<td>• We need to focus on Public Health messages; ‘What's good for the heart, is good for the head’.</td>
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Recognising problems early

Identifying Memory Concerns

- Patients with early signs of cognitive impairment are often just diagnosed with MCI rather than being referred for specialist assessment for dementia.
- The patients are seen once, diagnosed, and discharged – then what? It is hard to refer patient back into the system.
- When a family raises concerns but the person is in denial, (where possible) someone from the surgery will call that person in for a health review relevant to known conditions, and will conduct a memory assessment at the same time.
- Patients with suspected memory problems can be put into one of two groups: they are either worried, coming in very early and having no memory deficit, or they are in denial and only come after having been referred through anonymous phone calls by concerned friends or relatives.
- There is currently the issue that if the GP knows that a person is struggling in tasks of daily living, but the person scores well on the GP COG or an equivalent test, then MAS will not accept a referral (as the patient must reach a certain score). Patients can pass the short tests done by GPs if they are trying hard and concentrating, but at home they may be suffering from falls/accidents that can lead to crisis.
- There is sometimes a need for two or three consultations for those patients who are on slow declines to score high enough to be referred to MAS.
- GPs felt that the stage of diagnosis was rather varied in their surgery; some they diagnose very early, others are later on.
- There is a difficulty trying to see patients early. However, GPs are seeing more patients who want to come in and discuss their memory problems.

Challenges

- There seems to be two referral routes depending on the patient. There is one route for those patients who are uncooperative (such as patients who don’t want assessment), and another route for those who will go for assessment.
- Some patients have to travel far to get an assessment which acts as a barrier for assessments.
- Referral forms can be complicated.
- MAS can be delayed.
- In some cases, the patient’s family does not want to talk about dementia unless it is on their terms.
- Patients often delay going to MAS.
- For some patients, travelling to Eastbourne for a scan can be an issue, so they don’t go.

What is good?

- ACE is a good tool at picking up early changes.
- Sometimes scans are turned around in a timely manner (e.g. 6-8 weeks) and the bloods are also received quickly.
- For simple cases, MAS are fine in regards to getting an early diagnosis and follow ups are going well. However the more complex cases are trickier.

What can help?

- Clear signposting for staff who have concerns
- There should be one referral route regardless of the patient
- GP should be able to refer using them and the patients history and not have to wait until the scans are received
- SPFT should not refuse referrals as they should be seeing patient early
- Having to visit the hospital can be intimidating, being able to have GP’s give diagnosis or diagnosis given in home/familiar environment would be less intimidating.
- Dementia should be in primary care like diabetes, there should be dementia clinics in the practice
Delayed Diagnosis

The surgery had to wait until patient performs below a score before they can refer to MAS.

Increase risk (both physical and cognitive decline) of patient at home without treatment and support.

The GPs try to get more support for the patients (which they knew they needed) but they can’t refer to MAS and without diagnosis preventing access to support.

Delayed diagnosis, growing concern for patients health and well-being.

GP Case Study

“MAS should be an assessment of need and daily functioning, not score. GPs know the patients and will best be able to make the judgement whether the patient needs more support and if they do, what type of support they need. Whilst a diagnosis is relevant, it is more important to understand how a patient functions at home. For example, are they taking their medication? GPs can often see the beginnings of decline and should be able to start delivering intervention as they see appropriate.”
# Learning it’s Dementia

## Experience With MAS
- **MAS** should be an assessment of need not score.
- A delay occurs when there is a timely wait between bloods/initial tests and the assessment occurring. This wait can be difficult for patients when they are concerned about possibly having dementia.
- **MAS** can be disjointed, the package is not joined up and the process is not fluid (segmented).
- GP’s receive no feedback from MAS. Doctors don’t know if people have had a follow up or not. They also don’t know if patients are given extra information or whether patients have refused further information.

## Experience with Dementia Advisers
- **MAS** put some patients in contact with DAs, but DAs have little contact and input with GP surgeries. It is assumed that MAS are better at referring to DAs when and where it is appropriate, because GP’s don’t have full knowledge of the patient’s diagnosis and the services available.
- Some GP’s are being more proactive in referring to DAs and actively screening patients. There are a lot of patients who refuse the service as they think that it is irrelevant to them.
- DA referral forms are filled out before the diagnosis is given, which is the wrong time to refer as it is unknown if the patient has dementia. Some GP’s don’t tick the box as the diagnosis has not been given yet. They then assume that MAS refers on to DAs, so don’t refer patients later on.
- DAs are very good for support.
- DAs can come from outside the areas into clinics any may therefore be unaware of what the community has to offer and what services are available. They may not be in the best position to give advice, compared to those in Primary Care.
- GP’s feel they should have feedback from DAs.

## Support for Patients
- After a diagnosis of dementia is given to the patient they are then left in a state of limbo. The patients should not be dropped after point of discharge like they are at the moment.
- There should be more long-term follow-ups, the current process means that patients are assessed, diagnosed (labelled) and then discharged.
- There is then no one to look after the patient after discharge and the patient doesn’t necessarily come back in for help/support until they’re in crisis.
- Alzheimer’s Society and voluntary systems work much better at supporting patients.
- Patients are bombarded with information, then support drops off.
- Many GP’s thought that there was a need for someone who the person with dementia will know and recognise (like Cancer or Diabetes nurse).
- There is a need for a Dementia Nurse/Community Psychiatric Nurse in area who will co-ordinate and update patients care.

## Support For GPs
- It may be beneficial if GP’s could issue Mental State Reviews and make a diagnosis in straightforward cases, in order to save psychiatrist time so they could deal with the more complex cases.
- There is currently a lack of ownership, due to uncertainties between Primary and Secondary Care services about who is ultimately responsible for all the work and building up care packages.
- GP’s should be informed when a patient has been discharged.
- GP’s’ experience of complex case management should support them in doing this and knowing what services are available locally.
- GP’s are confused about what teams do what and think the structure is very complicated. There is lack of clarity on who in the community is there to support certain needs. There should be a GP resource detailing ‘Who does what’ (clarifying job roles) and what services there are across the locality.
Dementia Advisers and Support Services

Early Diagnosis
• Referred to dementia advisers

Patient may make contact with Dementia Advisers themselves

Crisis
• Later on contact with dementia advisors in extreme cases

Support for People Living with Dementia
• DAs are not used throughout the patient’s pathway. It is like there are two extremes - either early or late.
• Some patients are holding out too long before getting appropriate Adult Social Care support. The reasons for this are multi-faceted, for example: unaware of support on offer, not recognising support is required, denial around diagnosis, wanting to support their loved one for as long as possible without third party intervention, etc.
• There is poor access to social care. Usually families organise social care, unless the situation is urgent.
• People who need help the most (MCI/no family/no support) don’t get any support or access to services. Those with family and support will usually get through the dementia pathway and services as the family do what the DAs should do.
• There is nothing for people who are living in the in-between/mild stages of dementia.
• When a person becomes housebound they fall into a black hole and suffer from a rapid cognitive downfall.
• Community health teams are unclear on their roles in the dementia pathway.

After Diagnosis
• There is not the necessary requirement for all patients to have a meeting with dementia specialist after diagnosis (like with diabetes).
• There is no one responsible for the patient. The only checks done are the Annual Dementia Check. These are included in QoF audit but they do not involve any type of complex psychiatric review.
• There are delays with referrals to Living Well Service.

Crisis
• It is tricky supporting people in the community. Unless a crisis occurs then GPs are unable to step in.
• When a crisis does occur, there can be issues with the response time from other services e.g. social services. There is a lack of confidence with response services.
• Problems arise when dealing with high need cases, it is hard to get access to psychiatrists and have them go out to see patients.
• GP to CPN contact is infrequent and the contact they do have is usually when a patient has had a crisis or when GPs ask for the contact/support.
• GPs have reported feeling like they are “bothering” other services when trying to get more help/support.
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<th>What is needed</th>
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<tr>
<td>• A way to prioritise patients’ referral needs.</td>
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<td>• DAs providing pro-active support e.g. calling patients a few months after discharge to find out what support they have and what they want/need.</td>
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<td>• A good on-going relationship between patients and DAs. This should work to prevent crisis and also work with people in later stages and in nursing homes.</td>
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<td>• For crisis cases it is necessary to be able to access someone at an appropriately senior level to address issues holistically.</td>
</tr>
<tr>
<td>• There needs to be much better communication with social services in order to be able to provide better support to dementia patients.</td>
</tr>
</tbody>
</table>
GP Case Study

When a patient required further support the GP faxed the dementia team and informed the patient’s family that they should hear something within seven days. It was not until day eight that they turned up, there was no communication prior to them turning up so no one knew what was happening and did not know when to expect them. The doctor sent the fax and assumed that they would come out to the patient and then feedback to them but that didn’t happen.

In another case study, a patient was having severe hallucinations and the GP had to prescribe an antipsychotic drug as he could not wait 3-4 days for the mental health team to get to the patient. The doctors are able to reach consultants/psychiatrists if they keep ringing them back, however there are times when they don’t necessarily need to talk directly to a consultant; they just need a fast response from a member of the team when prescribing antipsychotic drugs. When they are not getting the necessary response from the psychiatric team, the person living with dementia has to be admitted to hospital as they are unsafe to stay at home and have nowhere else to go.

At times of crisis it is hard and often slow to get other services in to support the patient/ carer.

Poor Support

- Poor response time
- Poor communication channels- no feedback to GP
- No follow-up with family to inform referral has been received and what to expect
- Poor quality care and increased risk
- Avoidable hospital admission
Living with Dementia

What happens

What works well:
- Patient reviews are very effective as patients’ needs vary.
- Double appointments are given for dementia patient reviews.
- There are a good amount of interventions in Bexhill.
- Accessing social care is working well in Bexhill.
- Secondary psychiatric care has a good relationship with the specialist tertiary neurology services.

What isn’t working well:
- Poor integration between mental health and physical health needs. Patients are living with unmet needs.
- It is hard to manage people at different stages. The GPs are struggling to manage people with advanced dementia (where crisis occurs) and don’t have as much time for people who are in earlier stages.
- GPs are constantly fire-fighting. People can be missed when they come into the services at different stages, thus they miss out on support services due to having later (rather than early) diagnosis.
- Services are working in isolation.
Would should happen

- GPs need training to help them understand what they can do/what impact they will have.
- There needs to be clarity about what other services are doing.
- Specialist health visitors for the elderly - they should feedback into the practice to ensure consistency and immediacy.
- Dementia should be managed like a long term condition; this does not necessarily require a specialist in dementia.
- The patients need checking that they don’t have other condition which is being masked by their dementia.
- More action is needed to avoid crises.
- The Primary Care team needs to know more about the patient and have Multi-Disciplinary Team (MDT) input.
- Improve communication between Primary and Secondary Care.
GP Case Study

A patient example: There was a couple who were both ‘fine’ according to their Mental Health Assessments. However, the GP knew there was something wrong. The male patient’s symptoms were clearly being displayed when they came into the surgery and the female patient/carer reported alarming behaviour of the male at home. Because the patient did not give consent, the rules about patient confidentiality prevented staff from getting extra support from other services. The patients were self-reliant and self-funding and refused external carer support. When the GP kept referring the gentleman to the Memory Assessment Team they would feedback that the patient was fine throughout the assessment and no further action would be taken. Eventually, as a result, the male patient ended up being sectioned.
Advanced Care Planning (ACP)

**Challenges**

- Doctors are doing more and more ACPs and they are finding patients are now more willing to talk about it.
- ACP is being worked on due to the targets to reduce unplanned admissions in the top 2% most at risk. An element of this is to target the over 75s and have care plans put in place.
- The problem GPs have is that there is not much that they can do in eight minutes. There is not enough time to do ACP.
- In some practices ACP is not really done and does not come up as part of patient reviews. The conversation comes up in context of power of attorney conversations, however this can be hard and time consuming.
- ACP forms can be complicated and confusing.
- ACP tends to happen when the person needs more physical help.
- Many of the patients seen in nursing homes have had the opportunity for advanced care planning missed.
- ACP is mainly the GP’s role. DAs are not counsellors and do not provide the appropriate support to have discussions about ACP.
- There is a definite distinction between ACP and end of life care planning, which can be confused.

**What can help**

- ACP is being done well for terminal illnesses and therefore perhaps making dementia a long term condition rather than positioning it with mental health would improve things.
- More enhanced visits with patients.
- Something like key rings given out with key patient information on might be helpful.
- A small wallet-size or concertina card could be given out.
- To incorporate ACP into patient reviews.
- DAs could do ACP, but they would need to be trained appropriately.
- To be able to do this effectively the person should ideally have specialist background.
- Training on the differences between ACP and end of life care planning.
- Consideration needs to be given to completing documents such as “This is me”.
## Support for Carers

### What happens

#### What works
- It was generally thought that carer’s prescription is good. When the patient is discharged there is Care for the Elderly.
- Care Respite Emergency Support Services (CRESS) respite for the carers (but this is not advertised or known about).
- Respite care break is provided by third sector support. Third sector can provide better support as they can:
  - Deal with challenging patients when the spouse can’t always support the patient. If a patient refuses support or help from the GP they are unable to support the carer, but the third sector can; and
  - Get befriending services in to see difficult patients, which can help build patient trust and support.
- In some areas there are good volunteer support services.

#### What doesn’t work
- Patients often have extended time in hospitals because carers can’t cope at home. The carer’s needs are not being identified or met.
- There is often pressure from relatives for the patients to go into hospital; this is because there is a lack of alternatives.
- Carers don’t seem to get support. The GP does not see the carer/get to the carer independently of the person with dementia, to discuss their needs.
- It can be particularly hard for carers when patients refuse to be treated, for example: if they are in denial about their condition or if they do not yet have a formal diagnosis.
- There is no support for carers in the evenings or weekends.
- The support for carers is good when the person with dementia reaches palliative stage (support in hospices is good), but not as good for carers at earlier stages.
- It can be difficult trying to get hold of services when there are individual services for specific needs. This requires multiple persons to be contacted for one person’s multiple needs, e.g. treating patient needs, social services, mental health, carers support.
- Nursing home staff are not mental health nurses and are not getting the full support. This is becoming more common in care homes now with many dementia patients and staff not knowing how to cope.
- ACP has not always occurred because people do not want to talk about it. Carer can feel guilty about making decisions and having the conversations for the patient.
<table>
<thead>
<tr>
<th>What can help</th>
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<tbody>
<tr>
<td>• New way of diagnosing so that the support is there for carers.</td>
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<tr>
<td>• More should be done for families with a person diagnosed with dementia.</td>
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<tr>
<td>• Carer training.</td>
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<tr>
<td>• There needs to be clarification as to who is the point of call when the carer is struggling to cope.</td>
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</table>
Doctor/Patient Case Study

Sarah qualified from St Georges Hospital Medical School in 1998 and has been a GP partner at River Lodge Surgery, Lewes, since October 2002. Her clinical specialities are diabetes and women's health.

She strongly believes that general practice is the cornerstone of good NHS care. Nowhere else do patients get a joined up approach to their care, with someone who knows them well and looks after all their problems.

She has been involved in practice-based commissioning since it first started and thinks the CCG is the best way of providing the care her patients deserve.

- Dr Sarah Richards felt that there was a gap in what happens with the patient after they receive a diagnosis until they reach a point in time when the patient is at a stage of crisis.
- When the patient has a crisis their needs are not always dealt with appropriately.

GP’s Patient Example

A patient living at home with dementia received support from her daughter. The patient then got a Urinary Tract Infection (UTI) which exasperated their symptoms. Dr Richards worked with the daughter so that she could try and manage the patient’s symptoms and keep the patient at home. Dr Richards found that it was hard getting further support from the Mental Health Team and, as a result, the patient’s daughter was unable to cope and provide the appropriate support at home. The patient ended up being admitted to hospital. The patient was then discharged into a nursing home and, soon after, sadly passed away.

Dr Richards felt that if the patient could have got the necessary support in a timely manner then this outcome could have been avoided and the person with dementia and their carer could have had a better patient/carer experience; even if their deterioration couldn’t have been avoided. However, there was no rapid response at the time of crisis which left the patient unsafe to stay at home.
Patient and Carer’s Feedback

1. Memory Assessment Services (MAS)
2. Support After Diagnosis
3. Dementia Advisers (Das)
4. Memory Support Services (MSS)
5. Care Home In Reach (CHiR)
Memory Assessment Services (MAS)

Patient feedback was received by answering questionnaires:

1. Did you find the process for getting an appointment easy?
2. How long did you wait for your first appointment?
3. Were you given enough useful information about what would happen when you came to see us?
4. Did reception staff treat you with dignity and respect?
5. Did the nursing staff treat you with dignity and respect?
6. Did the medical staff treat you with dignity and respect?
7. Was the outcome from you seeing us explained in a sensitive way?
8. Was the outcome from you seeing us explained clearly?
9. Was the outcome from you seeing us explained in enough detail?
10. Were all your concerns addressed?
11. Were you given enough information after you left our service, e.g. about any medication, contacts with other services?
12. Have you been referred to a Dementia Adviser?

Patient feedback about their experiences with MAS was mostly very positive. Patients often reported high quality of care and experience of the services.

“Everyone was polite and helpful. Good service- should really say excellent.”

“All professional and nice.”

Patients often reported that communication with MAS team was very good, and staff were very helpful answering questions.

“They all impressed us with their patient, sincere and caring attitudes. They did not talk down to you. They listened to you.”

“Whole process straightforward and excellent.”

“We found all the staff exceptionally helpful and professional. We were put at ease as soon as we arrived and treated in a kind and polite way. We declined joining any groups or further assistance. This was the NHS at its best! We cannot fault the care and attention we received today at this clinic well done to you all and thank you.”

Carer feedback on behalf of the patient:

“I felt the staff were caring decent people and totally capable for expanding and improving the service if the commissioning was broader”

“Client was treated with respect and understanding.”
MAS-Issues

Referrals

Inconsistent waiting times of referrals. Some patients experienced long waits; in Jan-Mar 2015 15% of patients waited over four weeks for an appointment. Some had problems getting GPs to arrange appropriate tests and there were delays in receiving scan results.

“So long from start to finish- about one year plus.”

“Initial appointment very delayed.”

“Very protracted as couldn't get appointment without actually completing blood tests and scan first and then book appointment – a joined up process would be better.”

Access

Some patients raised the concern of practicality of locations. Some carers raised the concern of the practicality of supporting the patient to MAS when they themselves are in full time work:

“I could not get hold of someone most of the time - an email address should be provided. I am not used to people not working 5 days a week, there should be an email or 'choose and book' system. Improve hours and location, had to take a day off work as location is no good. Or a clinic on a Saturday morning? How would my mother have got there if I hadn't been able to take her?”

“To improve booking appointments at a time more convenient to patients and people associated with them.”

Communication

Some patients and carers felt that more information prior to the appointment would be helpful. They would like to have a better understanding of what to expect:

“For those who find reading paperwork difficult it would be helpful to have a telephone information line giving details of the assessment procedure that could be listened to from time to time as you go through the procedures.”
Whilst the majority gave positive feedback about receiving their diagnosis, some felt that delivery of diagnosis could be improved:

“Medical diagnosis explained in layman’s terms- we needed to search for answers on the internet.”

“As is often the case when one gets home there is the question – ‘What did they say about …’ or ‘What is that medical expression in layman’s language?’. So a few notes in “everyday English” would be appreciated and specific to each patient please, not a general guide.”

Patients also reported a lack of clarity as to the communication between GP, MAS and consultants. There can sometimes be uncertainty as to who will be advising for the next treatment option.

“Further follow-up in respect of non-medication issues, e.g. any change in condition, other avenues of support could be highlighted. Liaison with GP not convincing/disjointed”

**Carers support/communication**

Whilst patients often reported being given enough information, only 85% felt their concerns were addressed and carers tended to say they required more information.

“What’s about to happen was my wife’s fear”

“My carer would have liked some advice as to how I should cope with anxiety perhaps this is not your remit? I am completely satisfied thank you very much”

“More detailed information packs for carers or immediate family members so they know more about the different stages of dementia and how to cope”

Carers felt they were not given the time or chance to ask further questions or talk privately;

“The only negative thoughts I have of the session were that I found it hard to be fully honest in front of my mother concerning her violent behaviour. I feel there should be a private conversation also to address these issues.”
Signposting/further support

Both carers and patients felt the only treatment that MAS offered was medical and there should be further support on offer.

“There is a lot of information given about medication but very little about services available. Leaflets would have been helpful. To improve: quicker appointments and more leaflets”

“Perhaps some written information pack advising about additional services, benefits etc. would prove useful, I am not aware of any additional dementia contacts that could be made”

“Very informative. I would have preferred it if a community professional could follow-up regularly, the Dementia Advisers aren't qualified. To improve the service I would like to see a specialist team, including nurses, physios, OTs and a respite unit and home care staff specialising in dementia under one resource”

Patient feedback shows fewer than 50% take up of the Dementia Advisers service.

Summarising Quote

“The appointment took a while to come through, but after that everything was ok. Everyone was kind, polite and helpful and the doctor agreed that I should carry on taking the medication I am on. Seems to be an excellent service”
Support after diagnosis

How well are people living with dementia?
Many people with dementia and their carers are still not living well with the condition, and quality of life remains extremely varied. We all have a role to play in developing dementia friendly communities.

- 77% of people with dementia feel anxious or depressed
- 75% of people in the UK don’t think society is geared up to deal with people with dementia
- 67% of people with dementia do not always feel a part of the community
- 61% of people with dementia feel lonely some of the time
- 48% of people with dementia feel like a burden to their family
- 44% of people with dementia feel they lost friends after being diagnosed

From the Dementia 2012 report
## Dementia Advisors

### 2014-2015

### Service User/Carer Satisfaction Data

<table>
<thead>
<tr>
<th>At today’s meeting…</th>
<th>Quarter 1</th>
<th></th>
<th>Quarter 2</th>
<th></th>
<th>Quarter 3</th>
<th></th>
<th>Quarter 4</th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>At times</td>
<td>No</td>
<td>Yes</td>
<td>At times</td>
<td>No</td>
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<td>At times</td>
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<td>I felt involved</td>
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<td>0%</td>
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</tr>
<tr>
<td>We talked about thing that are important</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>92%</td>
<td>6%</td>
<td>0%</td>
<td>96%</td>
<td>2%</td>
</tr>
<tr>
<td>I felt encouraged to ask questions</td>
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<td>0%</td>
<td>0%</td>
<td>91%</td>
<td>6%</td>
<td>0%</td>
<td>96%</td>
<td>2%</td>
</tr>
<tr>
<td>I found the information given was helpful</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>94%</td>
<td>3%</td>
<td>0%</td>
<td>98%</td>
<td>2%</td>
</tr>
<tr>
<td>I felt listened to and respected</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>95%</td>
<td>2%</td>
<td>0%</td>
<td>100%</td>
<td>0%</td>
</tr>
<tr>
<td>I felt supported to do the things I want</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>94%</td>
<td>2%</td>
<td>0%</td>
<td>99%</td>
<td>1%</td>
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Total number of feedback forms received Jan – Mar = 117
Complaints/incidents

We have not received any complaints in this quarter or had any incidents.

Plaudits

We continue to receive positive feedback from service users and their carers. The most recent examples of these are:

Service User comments:

“I find it useful being with other people with the same problems and the carers are good and helpful”
“I enjoyed meeting new people”
“I enjoyed the involvement of the young multi-racial staff who were most supportive and fun. And indications that people take the, perhaps, inevitable decline seriously”
“I was impressed by the difference between the first grand assembly session and the intimacy of the subsequent working sessions. Staff were excellent”
“It’s useful learning how to help and understand different aspects”
“You’re a great team. Thank you for looking after us”
“It’s nice to be taken seriously”

Carers’ comments:

“I find it useful to have time to myself for doctor’s appointments or just a pint at the pub”
“The people are lovely”
Care Home in-Reach (CHiR)

Carer

“I found the Care Home in-Reach team to be very helpful. They gave us advice on several aspects of care. Challenging behaviour is a difficult thing to deal with and the workshops gave us lots of new ideas. As a result the staffs in our home are now able to respond in more appropriate ways”

Activity Worker

“A fantastic experience overall. This has brought new ideas to our workplace benefiting our residents’ well-being. The CHiR staffs are very approachable and make each session understandable and knowledgeable. I highly recommend this service”

Activity Worker

“They (CHiR) have given me a lot of ideas to work with residents, especially those with challenging behaviours and complex needs. It has been very useful and has given me more tools to work with”

GP Bexhill

“Very supportive for both the homes and care pathway. Helpful reviews and help in medication reduction/appropriateness of usage”
Patient Participation Group (PPG) Feedback

PPG Engagement meetings have included members from the following practices:

- River Lodge Surgery & Anchor Fields Surgery
- Groombridge & Hartfield Medical Group
- Buxted Medical Centre
- Quayside Medical Centre
- Heathfield Medical Centre

NB: The feedback detailed on pages 46 to 51 includes direct quotes from Patient Participation Group Members (PPGMs).
The Diagnosis

There are currently poor experiences with Mental Health; it feels as though mental health is a “Cinderella” service (a service felt to be "neglected, ignored or given little attention"). Even a 10% improvement would make a big difference.

Barriers: Diagnosis

### Diagram

- Stereotypes
- Access
- Fear
- Guilt
- Denial
- Embarrassment

Barriers: Access

There is poor access to services for people with mental health in the area. The assessments services are sparsely spread out and are a long way for people to travel. There can also be long waiting lists, causing people to go private just so that they can get things sorted out quicker.

Barriers: Stereotypes

“I hate diagnosing dementia because there are many who are coping and don’t want to be given the label”

The dementia label is not a good stereotype. Dementia can be difficult for people to accept. People can be conflicted, partly in disbelief and partly resentful.
Barriers: Denial/guilt/fear

Patients are also living in denial, thinking that memory problems are just a part of getting old. Couples are not admitting to doctors when there are problems going on. They are trying to cope alone; this is sometimes accompanied by embarrassment and guilt. Multiple Patient Participation Group Members (PPGMs) know of people who are still driving when perhaps they should not be.

PPGM has friends who plays golf, whom are physically fit but they are starting to have memory problems, but they continue to play golf as they are physically able to. Remaining physically active is most important.
Living with Dementia

WHO, WHAT, WHERE, WHEN

“WHO will support me?”

There is a lack of leadership and communication after diagnosis. The ideal would be a single point of access for each locality for the GP, carer and Person with Dementia (PwD). The dementia pathway is currently very confusing and complicated. It would also be good to have a handbook for patients.

In a local pharmacy, PPGM observed administration problems that impacted on dementia patients and their carer. For example, a lady’s husband had dementia. The consultant prescribed 4-6 weeks of medication. The lady was told to order 3 months in advance due to the Prescription Team being behind. This lack of efficiency through the system causes further stress for patients and carers.

“WHAT support will I get?”

There is nothing to offer patients diagnosed with dementia; so they do not want the diagnosis. Day care facilities are closing because the Adult Social Services are cutting back on expenses. The area doesn’t need new venues - they just need experienced staff to run support services.

“WHERE will I get support?”

It feels that there is no integration because of the cuts going on. The challenge will be trying to bring social services and health services together.

The pathway can be confusing when it changes across different counties; there needs to be sufficient explanation and consistancy so that everyone will know what to expect; so that no matter where you are in the country you can understand the main pathway.

“WHEN will I get support?”

People want to know what is available now! There is also a danger that, when services/interventions finish further down the line, the patient and their carer(s) will still need access and will not want to re-start the whole process again.
Caring for someone with dementia

Impact of diagnosis

It does not just affect the person; it also affects the carer. You have to give confidence to carers because they are protective of their loved ones and will also not want a diagnosis if they don’t feel that the support is there. They don’t want to see a door closed in their face. If there were more resources and services available carers would have increased confidence. There needs to be ways of letting people know that support they will receive to help them, and not stop them (the carer) from helping/supporting the PwD.

Relationships

Dementia patients really can’t cope without carers. How do we identify carers? Are GPs able to identify when someone is a carer? If they do, does the patient accept the diagnosis? Some patients refuse to go to MAS and won’t be pushed. Do GPs pick up on support for the carers? The problem is those who don’t get diagnosed and the carer then doesn’t get the support.

Coping with Caring

There needs to be more support for carers, such as day care services, as carers need to have a break. Social services that currently provide the support are getting worse and worse; they do a lot of paperwork and are lacking at providing any other support. On top of that, the support needs to be on time, more flexible and provide good quality care. Admiral Nurses would provide more support for carers; if they could work like Macmillan Nurses then this would be very good for support.

There is definitely a gap when it comes to support for carers. Carers can be old themselves; there should be a carers’ health team. Carers need to plan as well. Carers know they can’t cope forever. This does vary depending on the dementia patient and their rate of deterioration (the care they depend on and what the carer is able to cope with).
Carers Services

Care for the Carers is taking clinics into GP practices to offer their services. This helps the carers at the same time as the patient. When a patient goes in to see the doctor they just take the carer to one side after patient consultation and ask them how they are doing. This gives the carer the support they need.

A patient example is a family who have been struggling for 2-3 years and have been asking for help, but as the patient is in denial they don’t get the required support.
Dementia in care homes

PPGMs felt that people don’t get support once they are in a home, and are essentially “left”. What about those who do not have ticks in the right boxes, or even a diagnosis? For those living in both the community and care homes a diagnosis is not always feasible, so what happens to them? For example, patients who refuse to get the scans done as they fear hospitals. As they don’t have the scan they are not entitled to be referred on for further support.

PPGMs see people with dementia end up in hospital, be discharged into a residential home, and die. However, this can be prevented if dementia is caught early. By having an early diagnosis it enables people to plan, but for this to happen there needs to be a change of culture. There should be conversations about Advanced Care Planning with people before they reach late stages. Support groups are designing questionnaires but people don’t care, as they feel that there is nothing that you can do about it and it is just a part of getting old. However, talking about these things early can provide a comfort for the carer as they will then know what the patient wants.

PPGMs felt there should be more work on keeping people at home because it is cheaper. If one patient doesn’t fall you save a huge cost from the person not staying in hospital. One night in hospital costs the same as one week in a nursing home.

It was noted that not many homes have activity programmes. There is so much more that care homes can do to make the lives of people with dementia better.
Carer’s Experience

Today I did Dad’s food shopping. Tomorrow I’ll remind him to eat.

Every day I’m a carer.
Carer’s Experience

‘SC’ is the primary carer for her mother who has a diagnosis of Alzheimer’s dementia. She feels that the dementia pathway is not very clear.

Phase 1

When memory problems have prompted me, and/or my carer or family to approach my GP with concerns

SC had concerns about her mother’s behaviour, but did not know or even consider that her mother’s behaviour was the start of dementia. Due to her mother’s behaviour, the GP began an investigation into whether dementia was the underlying cause. The GP told SC what to look out for, such as eating habits, washing, etc. However, due to the nature of the behaviour, the family had to put their mother into a nursing home privately. The home was then able to do all the necessary checks and monitoring and feedback to GP.

SC felt that as soon relevant information should be provided as dementia is suspected. For example, what support there is, how to deal with other family members, what you should be applying for (e.g. financial support, power of attorney), where the focus should be (e.g. eating/ drinking) and then what to expect.

Phase 2

Learning that the condition is dementia

The GP was very good as he would talk to SC without there being an existing power of attorney and the GP was very supportive (there was no dealing with practice nurses). Short term advice was given by the GP/Occupational Therapist (OT) e.g. exercises and some adaptions.

There has been no GP review since diagnosis. GPs are aware of problems, e.g. continence, but have not followed up on them. Medications were also coming from different places, which was very confusing. When there were changes with medication it wouldn’t happen efficiently. SC had to keep chasing the pharmacy for the medication to be changed.

Some receptionists were aware of dementia and were very good. For example, when SC’s mother turned up to the surgery on the wrong day for an appointment, they would try and fit her in regardless e.g. flu jab and then inform the family of what happened. It would be useful for carers to receive text messages, to communicate if something had happened and any practical information.

The practice identifies SC as the main carer but not much else. The GP doesn’t have time to talk to SC about her ‘being a carer’. The only time they have to talk is about SC’s health. GPs definitely need more education in about dementia patients, but also education should be available to the carer.
Phase 3

Neither the Person with Dementia (PwD) nor carer was ever told about the Dementia Adviser (DA) Service. STEPS were helpful for advice and support. SC has had to be on call all the time. No carers respite has been offered, SC has had to privately arrange for carers to go on call one weekend a month to give her respite.

The OT suggested some changes to the house which were not practical for the PwD. The OT did not seem dementia aware in regards to respecting the choices they were still able to make and maintaining familiarity/consistency. The proposed adaptions would have caused (two week) disruptions and would have caused extreme stress for the PwD. The OT did not seem to accept that there are some things the person living with dementia was able to say yes/no to and decided they did not want the changes. There was no recommendation for dementia technology. SC feels that a Technology Assessment would have been and would still be very helpful.

SC felt that it would have been helpful to have six month psychological reviews and when the PWD has medication changes the carer should be made aware of whom to call and ask for advice if and when symptoms get worse.

Quote: (Information and Advice)

"The Alzheimer’s website has too much; you don’t know where to start. The advice needs to be a step-by-step leaflet of where to go at appropriate stages. Safety is very important. The biggest help would be information available as the dementia progresses. It needs to be easily accessible. Sometimes you just have one specific question that you would like to email a single point of contact. That way you can also come back to it at a later date as it’s written down."

SC feels that she does not know what will happen to her mother when the money runs out, nor does she know who to contact to discuss concerns. SC does not know which contact would help her understand whether her mother would be able to keep her paid-for carers (who keep her at home), or whether she will have to go into a residential home.
### Phase 4

**Getting the right help at the right time to live well with dementia, prevent crises and manage together.**

SC has had to run her mother’s care like a business. Her mother has private carers which SC has to manage. This includes rota, pay, shopping. SC has chosen to do this all privately as going through an agency is too expensive. Going through it privately also means that the support carers do more, but this is more responsibility for SC and is a constant juggling act.

SC does not remember the last Adult Social Care Assessment. It all took a very long time to get power of attorney and carer allowance. Everything took a number of attempts, as things kept coming back and was over-complicated.

When SC’s mother’s walking declined the GP referred patient to social services for occupational therapy, and then more help was received. The support received was good until the OT kept changing staff. The carer felt that they got lost in the system by OTs, and they don’t have the time to keep chasing the support.

When the ambulance service came out to a call with SC’s mother they were able to give some very useful advice.

### Phase 5

**Getting help if it is not possible to stay at home, or if hospital care is needed.**

When problems arise in people with dementia they need to be solved ASAP. This needs to be done to have as little stress for the person with dementia as possible. Stress can make things much worse by exacerbating symptoms. The person’s routine needs to be taken into account and disrupted as little as possible.

Social services seem to only be concerned with what would happen to SC’s mother if something was to happen to the primary carer (SC).

### Phase 6

**Receiving care, compassion and support at the end of life.**

If things decline SC wouldn’t know who to go to. Her support framework is other carers.
Engagement Summary
Engagement Summary

Clinicians’ Feedback

Prevention

- GPs do not feel that they have to the tools/support available to them to help support and give advice to patients who are diagnosed with MCI.
- GPs do not feel it is always appropriate to seek out and give patients a dementia diagnosis. They give multiple reasons for being reluctant, but one main reason is that they do not feel a diagnosis will benefit the patient in any way. The patient will be given the diagnosis which may actually result in reducing quality of life and wellbeing with no treatment, support or solutions to offer them. It seems almost immoral and unethical to give some patients a diagnosis when it seems like there is no light at the end of the tunnel.
- GPs acknowledge that the current system is re-active (rather than pro-active) and feel that early treatments and interventions need to be more accessible for people with MCI and dementia.

Recognising Problems Early

- Whilst some patients do not want to talk about memory concerns, GPs are seeing more people coming in with concerns about their memory. However, many of them are either given an MCI diagnosis or get too low a score on the cognitive tests to refer them to MAS.
- GPs feel that the system prevents patients getting an early diagnosis. When GPs are aware of early stages of dementia they are unable to refer them as the patients don’t have the right ‘score’ or they struggle to re-refer patients with MCI back into MAS. This can sometimes be a timely process during which time the patients may be declining without having access to any support or treatment.
- Whilst for simple cases MAS can be an efficient process, GPs feel that they should be able to refer patients sooner and based on patient’s backgrounds and not just patient scores.

Learning it’s dementia

- The current process of referring to MAS and other further support (DAs) can be disjointed and unclear. GPs are sometimes unsure whether patients have been given a diagnosis or not, whether they have been referred onto further support, what information the patients have been given at point of diagnosis and what support they have accepted.
- Some GPs think that DAs are good for patient support, but don’t have the best working relationship with them and they are unsure whether patients have been referred to the DAs. They feel that receiving feedback from DAs could help this partnership working.
- GPs mostly feel that there needs to be more support after diagnosis. This can be in multiple forms, such as more follow ups, more social support (which is best provided by the voluntary sector) and appropriate levels of information given at the right time.
- GPs feel there would be a place for a dementia point person (like cancer or diabetes nurse) to help guide, not just patients/carers, but also give GPs advice (about who teams are and what they do).

Dementia Advisers and Support Services

- The available support does not seem consistent throughout the patient’s journey. It feels like there is a lot of support given just after diagnosis (which may be the wrong time to give all the information) or in the later stages (perhaps when a crisis occurs).
• Those with family usually get through the pathway as family members do what DAs should do throughout the whole journey (making sure support is available when it is needed).
• When a crisis does occur GPs struggle to get a timely response from other services and feel that it can be hard to access the appropriate teams. They need more holistic workings.
• People with MCI don’t get any support or access to services.

Living with Dementia

• GP practices are implementing systems to improve the services for patients, such as double appointments given for dementia patient reviews.
• Those who are living in the mild stages of dementia often fall through a black hole and are forgotten about until a crisis occurs. GPs are so busy dealing with patients in crisis they don’t have time to check on those in the earlier stages on the pathway.
• GPs would like further training on how they can better support dementia patients.

Advanced Care Planning (ACP)

• GPs feel they are doing a lot more work to improve ACP, which is being supported by national initiatives.
• GPs feel that they are the most appropriately trained staff to do ACP with patients; they also have good knowledge of the patient.

Support for Carers

• The voluntary sector provide good support for carers, but carers don’t seem to get enough support and as result the PwD can suffer (e.g. prolonged visits to hospital as carers aren’t coping).
• There needs to be more support for residential and nursing home staff.

Patient and Carer’s Experience

Memory Assessment Services (MAS)

• Patient feedback with MAS is mostly very positive: there is good communication, staff are very professional and provide an excellent service.
• MAS issues: some patients have very long waiting times, accessing the service can be challenging (due to location and appointment times), communication could be improved (what to expect during diagnosis process and how the diagnosis is given) and more support for carers.

Support after diagnosis

• DAs: Positive feedback was received from patient feedback for the small number reporting accessing to it, in this engagement exercise.
• MSS: The service continues to receive positive feedback from service users and carers.
• CHiR: Positive feedback was received from carers, activity workers and GPs.
PPG Feedback

- **Barriers**: diagnosis, access, stereotypes and denial/guilt/fear

- **Living with dementia**:
  - Who do patients’ GPs/patients/carers contact for support, advice and guidance? A point person would be useful to help direct.
  - What support and treatment is there available? There needs to be more support available in the community.
  - Where can patients access support? The current pathway is confusing and they are unsure what the teams do or how to access them.
  - When can patients access the support? Patients want to know what there is out there for them now and whether they continue to access them in the long term.

- **Caring for someone with dementia**: a dementia diagnosis does not just affect the person living with the disease but also their carer(s). The patient-carer relationship is very important and there should be provision in place to support this relationship and help ensure that the carer’s needs are also being met. In order to effectively support the carers GPs need to make sure a carer is identified, supported and has access to carer services locally. PPGMs felt there is a gap when it comes to support for the carers.

- **Dementia in care homes**:
  - There needs to be more work to prevent people going into care homes; especially dementia patients. When a crisis occurs dementia patients may end up in hospital and it seems that the only solution is to discharge them back into a care home rather than their own homes where they are forgotten about.
  - People living in care homes will often miss out on getting a dementia diagnosis. Those with a dementia diagnosis are generally left with little support and miss out on a chance to do any ACP. There is the assumption that because a patient is in a care home they are getting the necessary support; however they miss out on regular reviews and interventions until a crisis occurs.

**Carer Case Study**

‘SC’ is the primary carer for her mother who has a diagnosis of Alzheimer’s dementia. She feels that the dementia pathway is not very clear.

1. SC lacked awareness and felt information about memory concerns and dementia should be given out as soon as dementia is suspected.
2. At point of diagnosis SC felt the GP was very good but the available supported services were disjointed. More carer support should be made available at this point in time.
3. SC was unaware of the DA service and felt the OT was not dementia sensitive. It would have been useful to know who to contact when her mother’s symptoms began to get worse, the information she had been given previously was too much and she didn’t know where to start. She also didn’t know what to expect and needed support planning for the future.
4. SC would have benefited from a Multi-Disciplinary Team (MDT)/holistic approach to her mother’s care. It was difficult trying to organise and access care and support for her mother. Some services she came in contact with were very helpful, giving her advice and guidance.
5. In a crisis situation problems need to be addressed in a timely manner with little disruption to the dementia patient’s routine. Social services did very little to support the PwD in a time of need.
6. If things decline SC wouldn’t know who to go to for support.
Current Dementia Services Model

- Delays
- Disjointed
- Fixed for all
- Medical Bias
The Future-
An emerging model of care

my golden ticket
my dementia
What Happens Next?
Next Steps

Learning from the evolving evidence base and feedback received in these engagement and consultation exercises will be used to inform a future model of care that will be co-produced with stakeholders and meets the following aspirations:

1. Use a Long-Term Conditions approach. This is because the majority of people with dementia also have other chronic physical health problems and/or comorbid mental health problems. In addition, the progressive nature of dementia and other long-term conditions means that most people have changing health and social care needs that need regular review over many years.

2. Offer specialist care for people with dementia and their family carers, within a multi-agency team that pulls together the skills of relevant professionals across the dementia network.

3. Offer a ‘Network’ of high quality services. This is because people's individual journey of care will differ depending on the subtype and severity of their dementia, comorbidities, social circumstances and care arrangements. Therefore, a network approach will ensure people can access the most appropriate information, care and support, at the right time, in the right place for them.

4. Bring together universal and specialist providers from all sectors that support people with dementia. They are an assets-based approach to commissioning that enables the optimum use of existing local resources.

5. Accommodate people who may have additional needs such as: Early Onset Dementia; Learning Disability; other neurological conditions such as Parkinson's disease or alcohol-related neurological disorders (which have a higher risk of developing dementia); and people from Black and Minority Ethnic (BME) groups.

6. Are easy to navigate, with a single point of access and a single care coordination system.

7. Integrate services to ensure a whole-systems approach involving all relevant health and social care stakeholders. Only by doing this, we will improve outcomes for people in a way that is affordable.

8. Harness the knowledge and experience of people using services and their family carers. As ‘Experts by Experience’, people with dementia should have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services. Where possible they should co-produce local services.
9. Prevent people from getting into difficulties by proactively supporting their condition and providing information, care and support, when they need it most, in a timely and responsive way.

10. Enable people to live as independently as possible, in their own home, if this is their preference.

11. Enables people to plan for their future care decisions early on in their journey with dementia, that gives people confidence that their wishes will be respected.

12. Treat people with dignity and respect.

The CCG would like to thank all patients and carers who shared their sometimes difficult stories and for clinicians who were so honest and open in their views in order to drive service improvements.
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Advanced Care Planning</td>
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<tr>
<td>ASC</td>
<td>Adult Social care</td>
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<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<td>CHiR</td>
<td>Care Home in-Reach</td>
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<td>CPN</td>
<td>Community Psychiatric Nurse</td>
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<td>CRESS</td>
<td>Care Respite Emergency Support Services</td>
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<td>DA(s)</td>
<td>Dementia Advisor(s)</td>
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<tr>
<td>HWLH</td>
<td>High Weald Lewes Havens</td>
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<td>NICE</td>
<td>National Institute for Health Care Excellence</td>
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<td>PwD</td>
<td>Person with Dementia</td>
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<td>MAS</td>
<td>Memory Assessment Service</td>
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<td>MCI</td>
<td>Mild Cognitive Impairment</td>
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<td>Memory Support Service</td>
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<td>OT</td>
<td>Occupational Therapist</td>
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<td>Patient Participation Group</td>
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<td>PPGM</td>
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