NHS
Herefordshire
Clinical Commissioning Group

Chapter 7: Living with Dementia

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Chapter 7: Living with Dementia

7.1. Introduction

Dementia is a term used to describe a range of neurological conditions, with the most common being Alzheimer's Disease (62% of all dementias in England[i]). NICE (2006) describes Dementia as "a disorder that affects how the brain works". Symptoms vary from person to person, but include a decline in memory, reasoning and communication skills with a gradual loss of the skills needed to carry out daily activities.

Historically, dementia was managed as a mental illness, however, in recent years there has been a shift towards its management as a long term condition. This presents an opportunity to diagnose and manage people in community settings, and to provide support to enable people and their carers to manage their own condition and maintain their independence.

A local needs assessment into Dementia was conducted in 2012. This chapter includes a summary of that work; the subsequent implementation plans and updates the gaps analysis around three locally defined outcomes:

1. Driving a Herefordshire wide culture change through raising awareness and understanding
2. Increase availability of early diagnosis of Dementia and support
3. Supporting people with dementia, carers and families to live well with dementia

This Chapter explores the prevalence for these conditions (subject to availability of information) before outlining models of care. The analysis is then presented in light of stakeholders' views and activity information before the recommendations are outlined for this area.

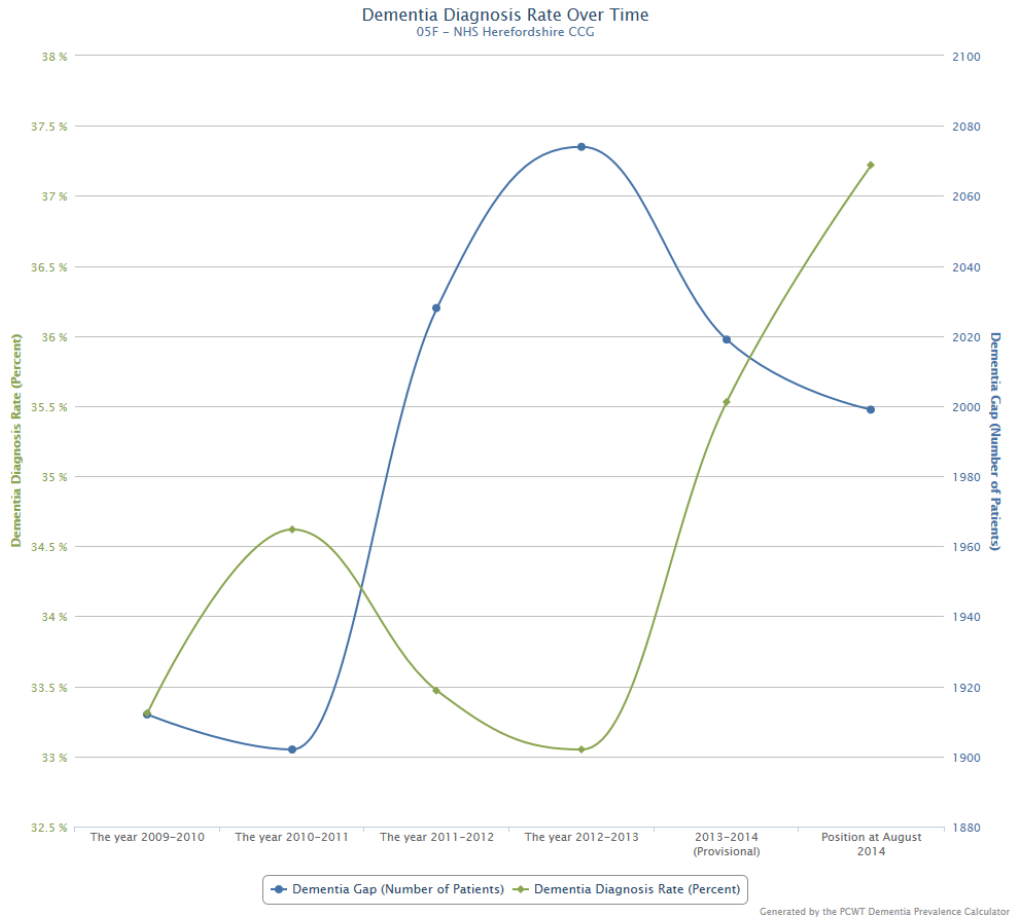
7.2. Prevalence

The two most common forms of dementia are considered to be Alzheimer's Disease and Vascular Dementia. There are also a number of rarer forms of dementia[ii]; fronto-temporal degeneration and

Lewy body disease being the most common[iii]. Alzheimer's disease is most common across all age groups; fronto-temporal and Lewy body dementia occurs more commonly in younger people (under age of 65). Dementia affects 800,000 people in the UK; with numbers expected to rise to 1,000,000 by 2021 and 1,700,000 by 2051[iv].

There are estimated to be approximately 3099 people in Herefordshire with Dementia[v], but only 35% of people were diagnosed in 2013.

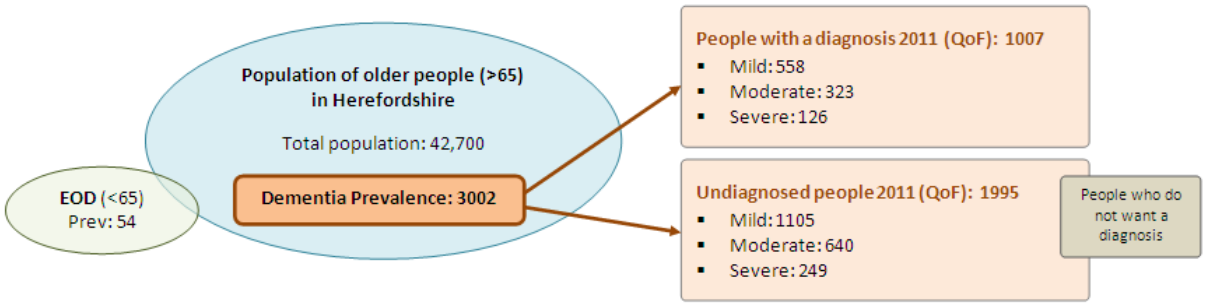
Figure 7.1 Dementia Diagnosis Rate over Time (2009-August 2014)



Current information shows that the trends in diagnosis rates have been slowly increasing. Information from September 2014 shows that the diagnosis rate is 40.95%. That is 1269 patients from 3099 expected number of people with dementia.

Since the severity of Dementia affects the level of support required, national data was used in the Dementia Needs Assessment to model expected severity levels in Herefordshire. This is shown in figure 7.2.

Figure 7.2. Prevalence of Dementia In Herefordshire



Source: Herefordshire Dementia Needs Assessment, 2012

Although the prevalence calculation has increased to 3099 in 2014, the increase is not statistically significant so figure 7.2 remains a valuable illustration of how the prevalence figure is broken down into severity.

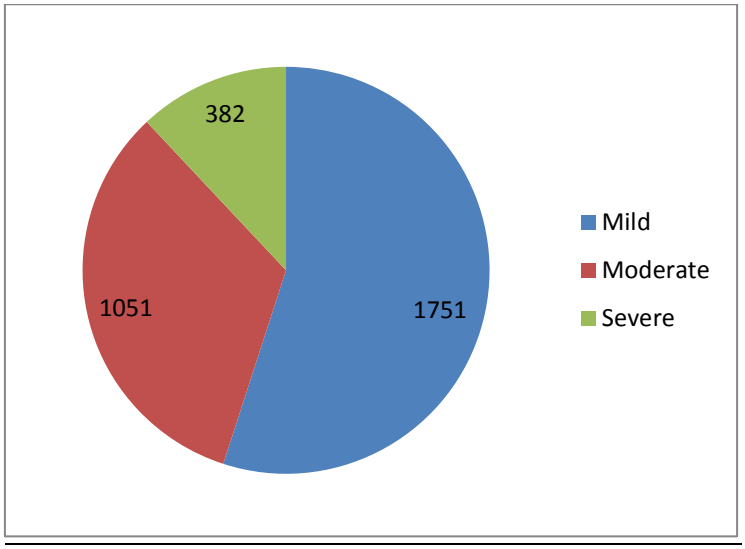
Early onset Dementia (EOD) affects people under 65 years. The expected prevalence of EOD is low at 54 cases. People with EOD have different needs. Individuals with Multiple Sclerosis, Motor Neurone disease, Parkinson's disease and Huntington's disease or those with a history of alcohol abuse are more likely to develop EOD.

People with Learning Disabilities (LD) are more likely to develop Dementia earlier in life and require a specialist approach to diagnosis and treatment. Data about Dementia prevalence for people with Learning Disability is not available in Herefordshire, however, there were approximately 500 adults with LD in 2013, and the number of people aged over 65 with LD is expected to increase by one third between 2011 and 2015.

Herefordshire has an older age profile than the average county in the UK; by 2015, the number of people aged over 65 is expected to rise to 46,900. Growth will be particularly high in the oldest age group of people aged over 80. There are older females than males in Herefordshire and this pattern is expected to continue in the future – this is relevant as there is a higher prevalence of Dementia in females. 20% prevalence is expected in people aged over 80 years old.

Using the national dementia prevalence calculator (2013) Herefordshire prevalence of 3099 people can be adjusted to take account of other factors such as number of care homes. The adjusted dementia prevalence is 3184 people. The figure 7.3 shows how the number of people is divided into mild, moderate and severe stages of dementia.

Figure 7.3: Estimated Proportion of People with Mild, Moderate and Severe Dementia living in Herefordshire.



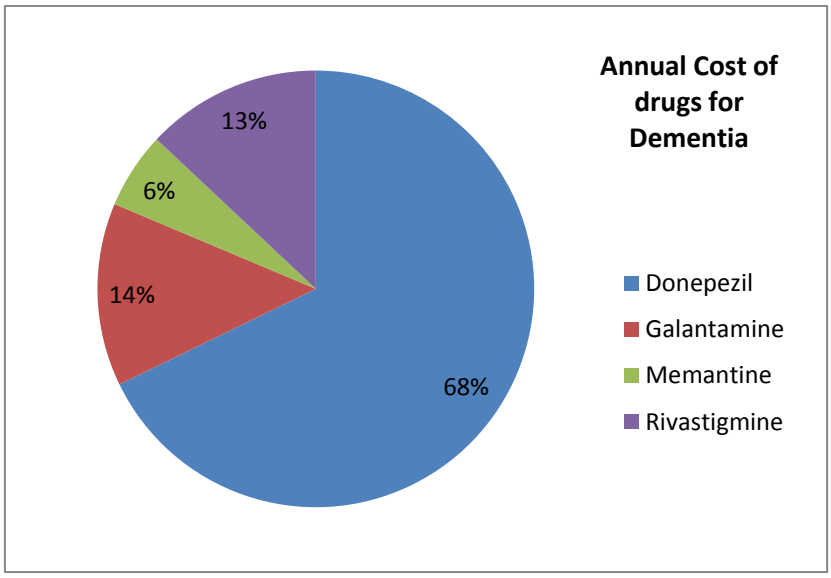
Source: The Dementia Prevalence Calculator, 2013

The prevalence of dementia can be divided into the number of people with dementia expected to live in the community and the number expected to live in a care home. As of August 2014:

- 445 people with dementia are expected to live in a care home
- 2739 people are expected to live in the community.

Local prescribing data shows that nearly £100,000 was spent on medication for people with dementia in 2013/14.

Figure 7.4: Herefordshire CCG Prescribing of Drugs for Dementia (By Volume 2013-14)



Source: Herefordshire Clinical Commissioning Group, 2014

7.3. Models of Care

7.3.1. Standards and Guidance

There has been many national strategy and guidance issued:

- National Dementia Strategy (February 2009)[vivii]
- Antipsychotics Report "Time for Action" (November 2009)[viii]
- National Clinical Director appointed (February 2010)
- Prime Minister's Challenge (March 2012) (Health and Care, Dementia friendly communities, research)
- Dementia State of the Nation Report (November 2013)
- Dementia G8 Summit (December 2013)

The National Institute for Health and Clinical Excellence, Social Care Institute for Excellence (2006) published guidelines in relation to dementia care. These can be used to compare against Herefordshire's provision and provide a foundation for developing the local model. In addition there are standards for memory clinics and dementia care standards for acute general hospitals.

7.3.2. Dementia Friendly Communities

Dementia friendly communities can be defined as:

"An integrated society where people with dementia live in 'normal' home-like situations throughout their lives with support to engage in everyday community activities." [ix]

The Local Government Association has developed guidance for local authorities in developing Dementia friendly communities[x]. This identified that community could become more dementia-capable by:

- increasing its awareness of dementia
- supporting local groups for people with dementia and carers
- providing more information, and more accessible information about local services and facilities
- thinking about how local mainstream services and facilities can be made more accessible for people with dementia.

Organisations have been signing up to the Dementia Action Alliance and 'Dementia Friends' - an education programme for the public is available.

7.3.3. Person-Centred Care

The model of care has shifted from a medical model to a model based on person-centred care (Kitwood 1997)[xi]. Brooker (2007)[xii] has suggested the acronym VIPS to encapsulate the broader meaning of person-centred care:

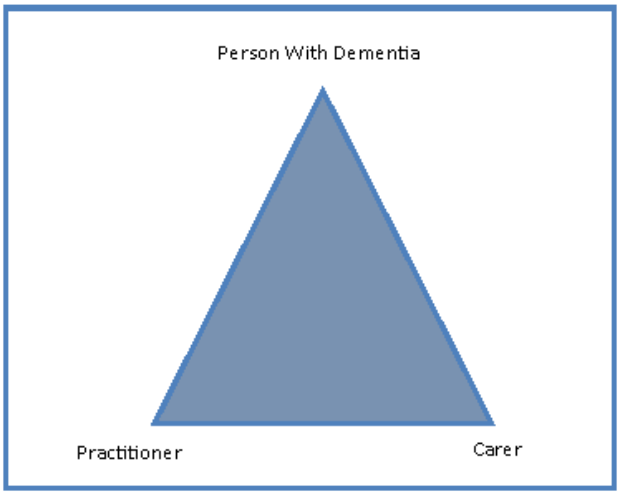
- **V**alues and promotes the rights of the person
- Provides **I**ndividualised care according to needs
- Understands care from the **P**erspective of the person with dementia
- **S**ocial environment enables the person to remain in a relationship.

Person-centred care is underpinned by a philosophy of personhood, which Kitwood characterized as follows: 'It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood 1997: p.8).

7.3.4. Triangle of Care

The Triangle of Care for Dementia describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. By involving carers, staff and services can ensure they have a fuller picture of the person's needs and how their dementia affects their behaviour and general wellbeing. In addition, carers are reassured that the person they care for is receiving the best and appropriate treatment possible.

Figure 7.5: Dementia Triangle of Care



Developed by the Royal College of Nursing in conjunction with the Carers Trust, guidance for the triangle of care[xiii] suggests that the best outcomes for patients, carers and practitioners are achieved when:

1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.

2) Staff are 'carer aware' and trained in carer engagement strategies.

3) Policy and practice protocols regarding confidentiality and sharing information are in place.

4) Defined post(s) responsible for carers are in place.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.

6) A range of carer support services is available.

7.3.5. Community Dementia Services

Informed by NICE guidelines and quality standards, memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) are a single point of referral for all people with a possible diagnosis of dementia. It should be a responsive service to aid early identification and should include a full range of assessment, diagnostic, therapeutic, and rehabilitation services to accommodate the needs of people with different types and all severities of dementia and the needs of their carers and family.

The service model focuses on the organisation of diagnostic and community services, to provide flexible and individualised care plans. Specialised services should be developed only where traditional services are deficient.

7.3.6. Inpatient Care

The Royal of Psychiatrists (Faculty of Psychiatry of Old Age) (2011) guidance on inpatient care for older people within mental health services states:

- The purpose of inpatient care is to provide specialist expertise with intensive levels of assessment monitoring and treatment unable to be provided in other settings.
- There should be clear and robust arrangements for urgent medical interventions and regular expertise available from geriatric medicine services.
- Community services should provide alternatives to inpatient admission. This should include crisis intervention and home treatment that is focused on the needs of the elderly.

The guidance also states that the number of beds for acute care originally identified by the Faculty (1-2 beds per 1000 elderly persons) will need to be adjusted according to local resources and demands (e.g. availability of home treatment, day hospital, local authority provision, service age cut off). Consequently some areas have reduced acute beds to 0.8 -0.67 per 1000 elderly population. Optimal bed occupancy for safe and efficient in patient bed management is 85%.

7.4. Findings

7.4.1. Dementia Friendly Communities

There have been a number of events in Herefordshire to promote Dementia Friendly Communities. In addition, a number of organisations have signed up to the Dementia Action Alliance making pledges to improve their services for people with dementia. In Herefordshire, at least ten organisations have developed action plans, including Herefordshire CCG.

A number of events were held during Dementia Awareness Week (18-24 May 2014) illustrating a willingness by the public and organisations to participate.

The promotion of dementia friendly communities, dementia friends and dementia champions forms one of three strands of work by the inter-agency Dementia Partnership.

Promotion of the above schemes remains an on-going activity. It is recommended that awareness raising of dementia by all partners continues.

Several areas in Herefordshire have started to consider how to make their area a dementia-friendly community. These are at early stages but the lessons should be shared with other villages, parishes and towns.

7.4.2. Multi-Agency Partnership

The Health and Wellbeing Board recognizes dementia as one of the long-term conditions affecting Herefordshire that would benefit from a shared partnership approach to ensuring that people and their carers are supported during all stages of their illness or caring role. The Dementia Implementation Partnership was created in 2013 to oversee the implementation of the Dementia implementation Strategy as well as build strong partnership working across Herefordshire. Eleven organisations have supported this work.

There are the three locally agreed outcomes developed by the Herefordshire Dementia Partnership.

1. Driving a Herefordshire wide culture change through raising awareness and understanding

2. Increase availability of early diagnosis of Dementia and support

3. Supporting people with dementia, carers and families to live well with dementia

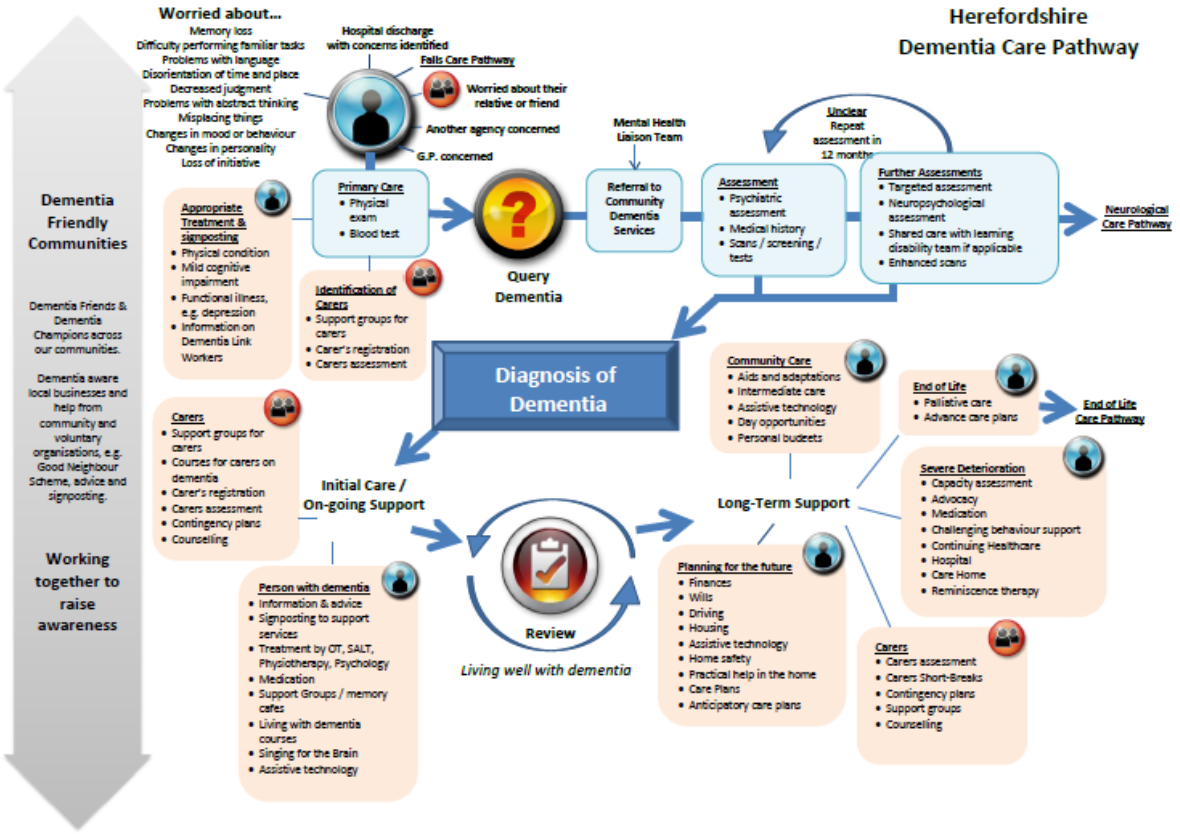
In addition to the action plan, the Partnership also developed an evaluation framework to monitor the impact of the activities on the lives of people with dementia and their carers. This is a good example of sharing a vision, activities and results with other agencies so that all elements can be monitored to see if outcomes are being achieved.

7.4.3. Care Pathway

We need integrated working that addresses housing, money, relationships. This needs to be addressed before the patient can approach recovery.
Mental Health Practitioner

During 2014, work commenced on a local dementia care pathway that recognised the needs of the person with dementia, the needs of carers and the role of the community, both pre and post diagnosis. Figure 7.6 is the agreed care pathway.

Figure 7.6: Herefordshire Dementia Care Pathway, 2014



Source: Herefordshire Dementia Implementation Partnership, May 2014.

Assistance is available pre-diagnosis and post diagnosis to both the person and their carer. This opens up access without the need for a diagnosis.

The design of the care pathway was consulted with the public through organisations and dementia events. People reported that they perceived the care pathway had the right elements that would impact on their perception of feeling supportive and address keeping well when living with dementia.

It is recommended that Herefordshire CCG continues to promote and utilise this care pathway.

7.4.4. Access to Memory Assessments

The average waiting times for a diagnosis after referral range from 2 to 13 weeks in the West Midlands. The recommended standard from the Royal College of Psychiatry is 4-6 weeks[xiv] . The current average waiting time from referral to assessment is four weeks. This is a significant improvement in waiting times since 2012 levels when the Dementia Needs Assessment raised this as a concern.

The table below provides data for expected benchmark activity for new referrals against calculated Dementia incidence in Herefordshire in 2014 and 2015.

New Cases by Year	2014	2015

Estimated prevalence (cumulative)	3,099	3,285
Estimated incidence (by year)	573	575
Benchmark Activity: indicative new cases ±	351	353
Yearly new patient appointments at Memory Clinic*	302	303
Positivity rate: new positive diagnoses in year ±	190	191

± based on NICE commissioning and benchmarking tool[xv]

* based on 6 new patient appointments per week [xvi]

Herefordshire CCG should continue to monitor the activity of the memory clinic to ensure that assessment is timely. With increasing referrals, the waiting times will grow.

7.4.5. Gaps in Services

There was recognition of the gaps in services by patients and practitioners.

a) The division of services between working age and older people meant that older people were poorly served for psychological support and patients were increasingly being "fitted" around existing services.

It is galling that certain psychological service only support people up to 65
Patient

Psychology support is poor for older people
Mental Health Practitioner

The Community Dementia Service has expanded the availability of psychology however there is insufficient information to ascertain whether there is a level of unmet need.

b) Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care. There is no dedicated provision for people with early on-set dementia particularly that addresses employment and other issues.

c) People with learning disabilities and those supporting them should have access to specialist advice and support regarding dementia. People with learning disabilities do not have sufficient support if they develop dementia. There is an innovative scheme in Herefordshire to develop a care environment dedicated for people with LD. Health and social care staff working in care environments where younger people are at risk of developing dementia, such as those catering for people with learning disabilities, should be trained in dementia awareness.

7.4.6. Inpatient Care and Discharge Planning

Delivering care in the right settings appears to be difficult at times. Stakeholder views raised the lack of inpatient beds and shortage of elderly mentally ill nursing beds in care homes. Mental Health practitioners identified a shortage of inpatient mental health beds, compounded by a lack of specialist nursing home placements. This resulted in local wards becoming mixed, with implications for management, as well as patients being moved out of county, with implications for care, support and expense. This was observed by carers too.

Beds have been cut at the stonebow unit, without beefing up the community care. This has led to more out of county placements and reduced flexibility, which is point of mental health- you never know when you'll need beds

Carer

We are short on beds. There is high demand, so we get working age adults in the older persons' beds. This causes problems with managing the mix of patients, ensuring everyone feels safe and we can't admit our own patients due to adult patients being in our beds.

Mental Health Practitioner

There are too few elderly mentally ill beds in the county, meaning that patients are placed out of county, which in turn impact on family visits and support. This leads to lengthy stays on the ward as there is nowhere to place them, which is upsetting for patients and families, who would like to be at home.

Mental Health Practitioner

There was felt to be a shortage of beds within the community into which to support people with dementia. The delay in discharges of patients from acute beds showed local incidents, however practitioners reported that the lack of beds was hindering admission for people requiring assessment and treatment. Some of the lengths of stay in a mental health bed suggest that a small number of people were not being supported in a timely manner to be discharged. Without an audit, it is difficult to confirm that they could have been discharged if the planning was effective / or care beds available.

Practitioners commented on the delays and insufficient supply of residential and nursing care home beds.

Council and social care finances have impacted on availability of care homes and care at home. It causes bottle necks for discharge and means that people are being managed in the community with higher levels of risk, so admissions are only for those with the highest level of need.

Mental Health Practitioner

There are not enough beds in the community to meet need. There are too few placements for patients with dementia and challenging behaviour, which results in them being placed out of county. Placements are able to refuse patients whose needs are too high and there is a risk of upsetting families due to a lack of choice.

Mental Health Practitioner

One of the issues related to the engagement of Social Care in arranging care packages.

The delay in organising panel papers, or due to placements falling through lead to more bed days and delays in discharge, restricting beds further.
Mental Health Practitioner

Some people living in care homes and hospitals may not be able to make their own decisions. They may sometimes lack the capacity to consent to treatment or care they may need. Deprivation of liberty safeguards (DOLS) can be applied to people in care homes and hospitals who meet the following criteria:

•aged 18 or over

•have a mental health problem such as dementia or a learning disability

•lack the capacity to consent to where their treatment or care is given

•need to have their liberty taken away in their own best interests to protect them from harm

In 2013/14, Herefordshire had made a total of 73 applications under DOLS, of which 39 were granted. This is a low number considering the number of care homes and demography. It was not possible to determine how many people out of the 73 applications had dementia.

People in hospital for physical healthcare might experience improved recovery if their mental health needs were taken into account. Liaison psychiatry offers a model of health care that embeds mental health provision into physical healthcare settings. The benefit of identifying people impacts on discharge plans and adherence to treatment plans by treating the person as a whole rather than a focus on the presenting symptoms. Herefordshire has limited liaison psychiatry and further investment would enable this provision to be available across community hospitals and general hospital.

7.4.8 Capacity and Support in the Community

People with dementia, carers and practitioners all acknowledged that care in the community is vital if people with dementia were to live at home for longer and that support to carers was fundamental.

There is a need for better education and engagement with families to understand the aim of services and how they can contribute. Relatives are a huge resource for us in meeting patients' needs but they can be overwhelmed. Quite simple support would mean improved patient care and Carer wellbeing.
Mental Health Practitioner

Alternatives to hospital and home treatment are elements of the care pathway that are under developed. Alternatives to hospital generally focus on adults with psychosis or other mental health

conditions. People with dementia that have severe or risky behaviours are often considered for hospitalisation, as limited community alternatives are available.

There needs to be more emphasis on visiting people in their homes so there is less need to be in hospital with more support from social workers and family support.
Patient/ Service User

We need more services to allow people to stay in their homes. Some GPs are not referring people early enough
Mental Health Practitioner

There is a need to strengthen skills in care homes/ community. Things like medication adjustments could be done in community to negate the need to admit patients.
Mental Health Practitioner

Feedback indicates that the work of the intermediate care service is valued in terms of aiding rehabilitation or resettlement in the community. There is little use of telecare or tele healthcare in Herefordshire for people with dementia. The main use is to contribute towards assessments in terms of wandering however technology could enhance the quality of life for some people with dementia and their carers. The greater use of telecare is an ambition of Herefordshire Council.

7.4.9. Education

Dementia Awareness sessions have been delivered in surgeries across both Herefordshire with further learning & development opportunities being offered to GP's and other medical practitioners. This includes Level 2 training, specialist training modules in specific areas such as; medicines management, good practice person centred care, special groups, i.e. learning disabilities, young onset, assessment tools and skills/early intervention, being delivered and additional learning at Level 3 training primary care liaison which also covers a wide range of areas is going to be delivered in 2015.

A multi-agency day - Living Well with Dementia in Herefordshire was held in June 2014. The purpose of the event was to engage with GP practices, Senior Clinicians, Practice Managers and other Health Professionals who are working with or supporting people with a diagnosis of Dementia. Nearly 100 practitioners attended the day and feedback showed that they valued the sharing of practice ideas.

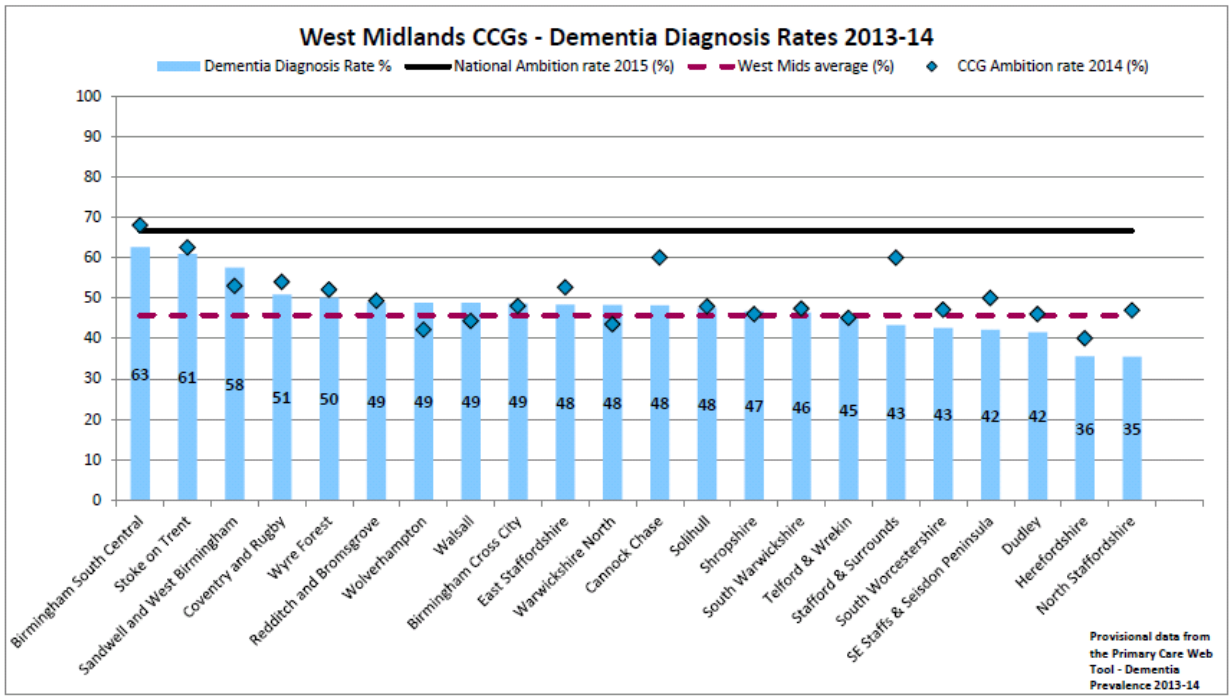
It is recommended that Herefordshire CCG supports the publicity of the dementia awareness sessions with GPs.

7.4.10. Diagnosis Rates

As of September 2014, Herefordshire had 1269 people diagnosed with dementia. This is the equivalent of 40.95% dementia diagnosis rate per 100,000 population.

The diagnosis rate across the West Midlands shows variation from 35% to 63% in 2013/14, with the England average as 46% as figure 7.7 shows:

Figure 7.7: Dementia Diagnosis Rates 2013-14 in the West Midlands.



Source: Primary Care Web Tool, 2014

Herefordshire is making progress as the diagnosis rate as of 2013/14 was up thirty-three per cent since 2012/13. However this is great variation between GP practices (between 19% to 62%) and further diagnoses are required by April 2015.

Explanations for the dementia diagnosis gap could be coding issues in primary or secondary care; poor case finding of vulnerable patients; lack of targeted screening and further education required across practitioners to aid with recognition of cognition or memory impairments. Other community health staff are a vital part of recognising and identifying people that require assessment or support. To encourage practitioners to signpost to sources of support, information on the care pathway and referral routes should be cascaded, with specific training offered to other community teams.

Recommendation is to work with Primary Care to ensure that all people with dementia are recorded on the register and that the coding is standardised across Herefordshire. The CCG can offer support in reviewing the register.

7.5. Recommendations

Although there has been ongoing work to improve dementia awareness, the diagnosis rate and feedback from people with dementia indicate that there remains a lack of understanding in the county, affecting how supported people feel. Continued awareness raising of dementia within our communities and across all health services will enhance the number of people that come forward for an assessment and receive help with future planning and their quality of life. All parts of the NHS should form part of the greater workforce able to identify and enable patients to access an assessment. Voluntary and community organisations can equally identify people who may be in need of assistance, including assistance from a community dementia service.

This Needs Assessment reinforces the Dementia Needs Assessment (2012) that gaps still exist in provision for people with early onset dementia and people with learning disabilities. Some forms of support are restricted by capacity such as availability of nursing home beds within the community, making it difficult to discharge patients from hospitals. Other forms of support are restricted by capability of organisations to offer dementia care.

There has been positive change since the Dementia Needs Assessment (2012) with the introduction of the community dementia service and agreed care pathway. This offers a holistic approach to dementia care, in partnership with GPs, care homes and the voluntary sector. The creation of an interagency dementia action plan during 2014 demonstrates that organisations are actively working together to provide information, advice and support, including access to diagnosis, and assistance for carers. New developments such as community arts and early onset self-help groups are in recognition of the local needs that people have. And yet, although Herefordshire has a low rate of diagnosis, awareness of dementia by people living with dementia and their carers will drive the need and expectation for further services.

The recommendations are:

- To support the work of the Dementia Partnership and the development of dementia friendly communities across Herefordshire.
- To continue to raise awareness of dementia including a programme of education for practitioners to improve dementia care. This should result in earlier detection, allowing improved planning with the person and their family.
- To develop liaison psychiatry service that will identify people with dementia and improve clinical care.
- To improve support services for people with early onset dementia
- To improve support services for people with learning disabilities and dementia.
- To review availability of psychology for people with dementia against the level of need.

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