



Shropshire Clinical Commissioning Group



Shropshire's Dementia Strategy

2014-16

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1.0. Introduction

In July 2013 a Shropshire Dementia Strategy Implementation Plan was compiled jointly between Shropshire Clinical Commissioning Group, the Local Authority, local health partners and local voluntary organisations with the purpose to develop services for people with dementia which meet the anticipated increase in prevalence and more efficiently deliver key outcomes that reflect improved quality and cost effectiveness of care and support services (Appendix A).

The document sought to provide a summary of the growing needs of the local population and a proposed model for the future commissioning of integrated dementia care. It outlines a series of modules of redesign some of which have been implemented and some which are proposed but together optimise quality whilst minimising duplication, gaps and unnecessary costs.

Shropshire's Dementia Strategy 2014-2016 aims to follow on from, and refresh the 2013 Strategy Implementation Plan by:

- Continuing with and further developing the valuable work which has already been undertaken.
- Refreshing and implementing those modules which were at proposal stages.
- Identifying and implementing new priorities for dementia across local health and social care services, taking into consideration and incorporating new national policy and guidelines including the Better Care Fund, the Care Bill 2014 and the NHS Operations Framework 2014-15.

The strategy 2014-16 outlines what services are currently in place and work to date in Shropshire, how we propose to build on existing work programmes and how we intend to further develop services outlined in a robust action plan; with the aim to deliver improved quality of care and health outcomes for people with dementia and their carers across Shropshire.

2.0. Shropshire's Vision

Based on the three key themes of the National dementia strategy; the person centred outcomes identified in **The National Dementia Declaration: A Call to Action** (1), which describes seven outcomes people with dementia and their carer's would like to see in their lives; the priorities for the local Health and Wellbeing Board and the Joint Health and Wellbeing Strategy and patient and carer feedback; the vision for Shropshire is:

“To be a dementia friendly county whereby people diagnosed with dementia and their carer's feel well supported by their communities, whereby they can maintain independence for longer and when needed, are able to easily access appropriate, person centred, high quality integrated health and social care and support services at all stages of their illness.”

3.0. The objectives of the strategy

- To raise awareness and understanding of dementia within all communities
- To better identify those at risk of dementia
- To ensure early diagnosis and early intervention

- To ensure all people diagnosed with dementia and their carer's have access to high quality care and support services,
- To ensure people are able to live well with dementia and reduce the risk of crisis.
- To ensure high quality end of life care.

4.0. What is dementia?

Dementia is overwhelming both for the individual and for their family and carer's. The term "dementia" describes a range of symptoms which may include memory loss and difficulties with the ability to think, solve problems or communicate effectively and it is caused by diseases of the brain. Because dementia is progressive these symptoms will gradually get worse; contrary to common belief, dementia is not a natural part of ageing it can occur at any age.

The common types of dementias are as follows:

- Alzheimer's disease – accounts for 62% of dementia diagnoses. The brain's chemistry and structure changes causing brain cells to die.
- Vascular dementia – 17% of cases. Caused by strokes or small vessel disease.
- Mixed dementia – 10% of cases. The diagnosis is both Alzheimer's disease and vascular dementia.
- Dementia with Lewy bodies – accounts for 4% of cases. Caused by irregularities in brain cells leading to symptoms similar to Alzheimer's disease and Parkinson's disease.
- Frontotemporal dementia – 2% of cases. Affecting the front aspect of the brain causing behaviour and personality change. (2)

Of the subtypes, Alzheimer's disease is the most common, especially amongst older people and women, whereas Frontotemporal dementia accounts for many of the early onset cases affecting younger men. (3)

In later stages of dementia a person will require increasing amount of support to carry out day to day tasks, however many people live well for years after their diagnosis and are able to maintain independence especially if they have timely access to information, advice and are well supported in their communities. (2)

5.0. The Impact of Dementia

5.1. Global Context

Dementia is one of the biggest global public health challenges that our generation is facing. The world's population is aging; people are living longer due to improvements in health care and advances in technology and this has led to an increase in the numbers of people with non-communicable diseases such as dementia (4).

Research to find causes and risk factors for dementia is ongoing and it is thought that many factors including genetic background, lifestyle and medical history can contribute to the onset of dementia. However, the main risk factor for most dementias is advanced age.

Worldwide, over 35 million people currently live with dementia and this is expected to double by 2030 and more than triple by 2050 to 115 million. (5). Many people with dementia also have other long term conditions affecting their physical and mental health and wellbeing.

Of all long term conditions, dementia and cognitive impairment are by far the most significant contributors to disability, dependence and in affluent countries transition into care home settings. Dementia contributed to 11.2% of all years lived with disability amongst people aged over 60 which is more than stroke 9.5%, cardiovascular disease 5% and cancer 2.4% in accordance with figures estimated by the (6).

5.2 National Context

5.2.1. Prevalence

It cannot be emphasised enough that dementia is one of the biggest health crises facing the UK. There are approximately 800,000 people living with dementia in the UK and it is projected that this will rise to 1 million by 2021 and to 1.7 million by 2051 (7). Projections for the UK show an increase of 156% in the number of people with dementia between 2005 and 2051 (3).

Dementia can affect anyone of any age, however it is estimated that one in six people over the age of 80 and one in fourteen people over the age of 65 has a form of dementia. Research shows that one in three people over the age of 65 will develop dementia before they die (7).

It is also estimated that approximately 15,000 people under the age of 65 have dementia although this number is likely to be a significant underestimation (8). The prevalence of early onset dementia is higher in men among 50-65 year olds; by comparison late onset dementia is marginally more prevalent in women than in men (3).

In the UK, it is estimated that there is a greater proportion of young onset dementia within Black and Minority Ethnic groups, there are approximately 12,000 people from Black and Minority Ethnic (BME) groups with dementia and of this amount, 6.1% among BME are early onset dementia compared with 2.2% for the UK population as a whole (3).

5.2.2. Death rate attributable to dementia

The proportion of deaths attributable to dementia gradually increases from 2% at age 65 to a peak of 18% at age 85-89 in men, and from 1% at age 65 to 23% at age 85-89 in women. There are 60,000 deaths each year that are directly caused by dementia, if we could delay the onset of dementia by five years this would halve the annual number of deaths due to dementia in the UK (3).

5.2.3. The cost to the person

According to the Alzheimer's society, many people with dementia and their carer's struggle to maintain a good quality of life and to live well with dementia, partly due to stigma and misconceptions, for example only 23% of people think it is possible for people with dementia to live on their own. Depression, isolation and loneliness can be a significant problem for a person living with dementia, 38% of people with dementia feel lonely and 62% of people with dementia who live alone feel lonely (7).

Within the UK there are estimated to be 670,000 carers of people with dementia (7). Family carer's provide much of the support for people with dementia and they themselves can find it difficult to manage their own physical and mental health needs and are at greater risk of stress and depression particularly if they received less social support (2).

5.2.4. Financial cost

The annual cost of dementia to the UK is estimated to be around £23 billion with an additional hidden cost of £8 billion which is the value of the work done by family carers supporting people at home. Of the total number of people diagnosed with dementia in the UK two-thirds live in their own homes with the remaining third live in a care home setting (7).

The table below outlines the total annual cost calculated per person with dementia, living in different care settings with different stages of dementia:

Table 1 – Protecting Older People Population Information System (9)

People in the community with mild dementia	£16,689
People in the community with moderate dementia	£25,877
People in the community with severe dementia	£37,473
People in care homes	£31,296

5.3. National dementia challenges

National reports and documents clearly state there is more to be done to address the dementia epidemic. According to the National Dementia Declaration, public awareness of dementia is high but understanding is poor and a stigma around dementia remains as a significant barrier to people seeking help. Currently only 44% of people with dementia in the UK have a diagnosis.

Equally, NHS and social care systems have not developed services to address the fact that the population is aging and therefore dementia will become much more prevalent meaning people with dementia and their carer's will have greater health and social care needs.

5.4 . Local context

5.4.1 Population profile

Shropshire has unique health and social care challenges due to its rural nature and sparse population which is 306,129 of which 49.5% are men and 50.5% are women. This population is getting older when compared to the national average, the number of people aged 65 years and over in Shropshire accounts for 20.6% of the total population (10).

Shropshire has an aging population and has a greater proportion of its population in all the age groups above and inclusive of 45-49, with projections set for the 65-84 age group to increase by 70% by 2031 with the 85 years and over age group projected to increase by 194% by 2031. With an aging population, the prevalence of dementia in Shropshire will increase. In 2011, 98% of the total population of Shropshire were classified as white, with 1% of the total population classified as Asian or Asian British ethnic groups (10).

5.4.2 Prevalence of dementia in Shropshire

In 2011/2012, the percentage of adults over 18 years living with dementia in Shropshire was 0.68%, significantly worse than the national average of 0.53%; it is important to note that for the same period, Shropshire has a significantly higher percentage of adults over the age of 18 with a learning disability (0.58%) than the national average (0.21%); people with learning disabilities are at greater risk of developing dementia.

According to most recent figures from the Practice Level Dementia Prevalence Calculator 2012-2013, there are a total of 5026 people (Adjusted National Dementia Prevalence rate) living with dementia in Shropshire of which 3,254 are living in the community and approximately a third of the total number; 1,772 are living in a care home (11).

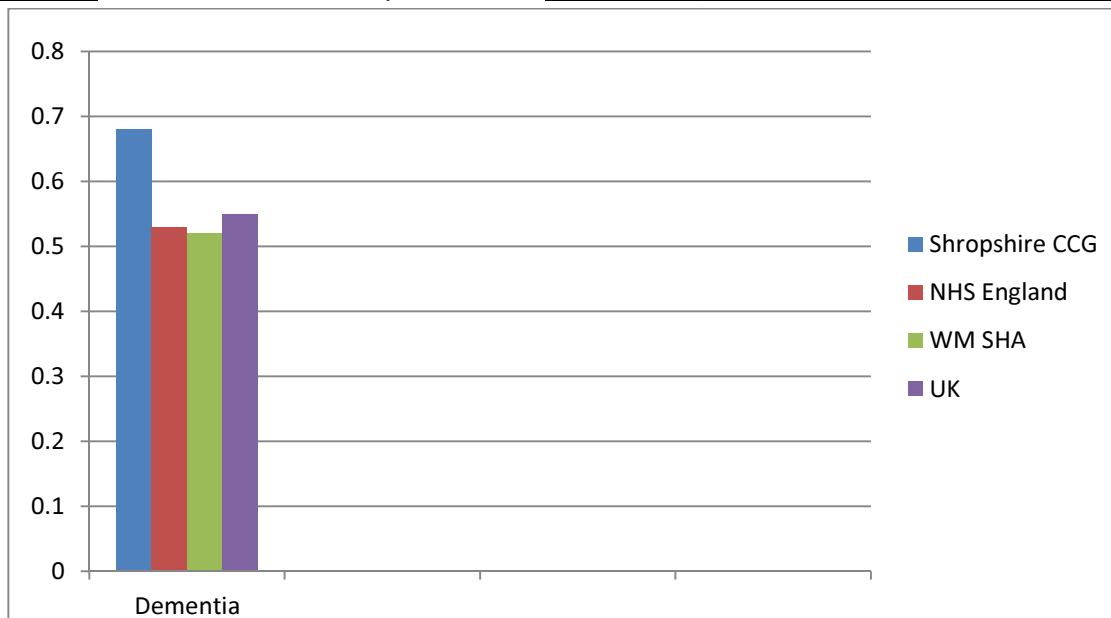
The national target for dementia diagnosis is 67%. This means the percentage of what might be the expected prevalence as calculated by the "Prevalence calculator".

The dementia diagnosis rate for Shropshire according to the Practice level dementia prevalence calculator 2012-13 is 43.7% (11).

However, the prevalence of dementia using QOF prevalence data is 0.7%.

Rate of diagnosis: 7.3 per1000 of the population.

Table 2: QOF 2012 dementia prevalence: <http://www.gpcontract.co.uk/browse/5M2/12>



The percentage diagnosis rate shown by the prevalence calculator weights the predicted prevalence according to number of care home beds and the age of the population. In Shropshire there is an above average number of care homes and an ageing population. The calculator is suggesting that Shropshire's diagnosis rate should be higher than other regions where demographics are different. Feedback from practices suggests that there is an under diagnosis of dementia in care homes for a number of reasons including:

- Concern that a positive diagnosis may lead to a change in care provider where the current care provider cannot meet CQC regulations for the care of people with dementia. This may not be of benefit to the patient.
- A perception amongst clinicians that a diagnosis would bring little benefit where the patient is settled.

This is likely to explain why Shropshire appears to be performing less well according to the data collected through the dementia "Prevalence Calculator" whilst appearing to perform well according to QOF prevalence data.

Providing a patient with a formal, early diagnosis is important and helps patients and their carer's take control, and benefit from appropriate treatment, access support and information and plan their future care according to their needs and preferences.

The dementia Direct Enhanced Service scheme was introduced to the GP contract during 2013-14 to encourage case finding by opportunistic assessment of patients at risk of dementia and offering specialist care planning with the aim to help increase diagnosis rates. The dementia enhanced service has been extended to 2014-15 and aims to build on last year's enhanced service by putting in place additional measures to improve services for patients diagnosed with dementia including increasing the health and wellbeing support offered to carers of patients diagnosed with dementia.

The Commissioning for Quality and Innovation (CQUIN) framework for dementia aims to support improvements in the quality and innovation of dementia services. Shrewsbury and Telford Hospitals Trust (SaTH) are participating in the national dementia CQUIN thus contributing to increasing diagnosis rates through case finding amongst patients admitted as an emergency over the age of 75 years; undertaking a diagnostic assessment and referring on for specialist diagnosis of dementia and appropriate follow up and intervention.

Shropshire's Dementia Strategy and action plan outlines work programmes which focus on raising awareness of dementia and reducing the stigma associated with it; this will have profound benefits on improving diagnosis rates and enabling people to receive timely support and information.

6.0. Strategic drivers shaping Shropshire's Dementia Strategy

The National Dementia Strategy "Living well with Dementia" 2009 (13) sets out seventeen recommendations for NHS, Local Authorities and other organisations to take to improve dementia care services. These recommendations focus on three key themes:

- Raising awareness and understanding of dementia
- Early diagnosis, intervention and support
- Living well with dementia

These key themes were carried on and further developed through The Prime Minister's Dementia Challenge, March 2012 (14) and Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy, September 2010 (15); outlining further need for improvements to dementia care to be undertaken more quickly, focussing on increasing diagnosis rates and improving the awareness needed to support people with dementia and their carer's. It also details plans to improve dementia research.

NICE quality standard 30 for supporting people to live well with dementia applies to all health and social care settings and outlines the importance of a person-centred and integrated approach to providing care and services for people with dementia and that this is fundamental to delivering high-quality care (16).

One of the five domains within The NHS outcomes framework (17), domain 2: "Enhancing quality of life for people with long term conditions" includes the intention to enhance the quality of life for people with dementia, from which outcomes framework indicators and CCG level indicators have been set to measure:

- i) Estimated diagnosis rate for people with dementia
- ii) People with dementia prescribed antipsychotic medication.

A new placeholder was included in The Adult Social Care Outcomes framework 2013-14 (18), domain 2: "Delaying and reducing the need for care and support", which is specific to Dementia: "a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life", which is a key priority across Adult social care and the NHS requiring integrated working at a local level.

At a local level; the Joint Strategic Needs Assessment (19) identifies the ageing population within Shropshire as one of the key challenges facing health and social care provision across the county and equally it identifies the importance of people being supported to age well. The Joint Health and Wellbeing Strategy (20), outcome 3 is for "Better emotional and mental health and wellbeing for all" and a clear priority within this outcome is to make Shropshire a 'Dementia Friendly' county to enable earlier diagnosis and improved outlook for people with dementia. The strategy outlines future action required in relation to the priority including having an understanding of the numbers of people with dementia and what support they need; raising public awareness; provide information at the right time and creating a dementia friendly Shropshire.

This strategy also links in with Shropshire CCG's Long Term Conditions strategy and Shropshire Council's Carer's Strategy.

7.0. Interdependencies

7.1. Better Care Fund

The Better Care Fund was announced in the spending review in June 2013 and is the pooling of resources across health and social care boundaries with the aim to integrate health and social care to improve people's experience of health and care, improve outcomes and ensure efficient use of resources (21). Local plans have been drawn up by Shropshire CCG, Shropshire Council and local health and social care providers outlining how the fund will be used to address the challenge to improve services and outcomes for the people of Shropshire and make the local health and social care system financially sustainable into the future. The key priorities set are:

- Prevention (carer's support and liaison)
- Early intervention (early identification, diagnosis, treatment and support)
- Managing and supporting people in crisis (RAID, Integrated Community Services)
- Living independently for longer (rehabilitation, re-enablement, compassionate communities, community care coordinators, telecare and end of life care)

Within the scope of the Better Care Plan 2014-16 there is a commitment to improving diagnosis and support for people with dementia and Parity of Esteem is assured for the local population, with Shropshire's Health and Wellbeing Board having identified mental and emotional wellbeing as a priority, in particular supporting people with dementia.

7.2. Future Fit

The reconfiguration of acute and community hospital services with consideration to the health and social economy as a whole with clinical design principles applicable to three main areas of health care delivery including long term conditions and frailty and elderly. Services for dementia will be included in this reconfiguration.

7.3. The Care Act 2014

The Care Act 2014 is a significant reform of care and support which will put people with dementia and their carer's in control of their care and support, giving them a better understanding of what they are entitled to. The Care Act also includes a requirement for the provision of prevention services, a duty to promote the wellbeing of individuals and a duty to promote integration between health and social care services all of which have the potential to positively impact on the lives of people with dementia and their carer's.

The new Act will help to improve the independence and wellbeing of people with dementia and their carer's, the local authority has a duty to arrange services that help prevent or delay people deteriorating whereby they would need ongoing care and support. This includes identifying people across Shropshire including those with dementia and their carer's who have care and support needs that are unmet and also identifying carers who have support needs which have not been met.

To help keep people independent and well Shropshire Council is required to work with local communities to identify and further develop community support and resources, helping people to access them, for example dementia support groups such as the Alzheimer's Society dementia café's.

The Care Act clearly states that local authorities will need to provide information and advice around the types of care and support available locally such as specialised dementia care, befriending services and residential care. Shropshire Council will also need to provide information about how people with dementia and their carers can get the care and support which is available.

In order for Shropshire Council to understand what dementia services are likely to be needed in the future and what types of support should be developed they have a duty under the Care Act to engage with local people about their needs and wishes (22).

8.0. Stakeholder/Public Engagement

In October 2013 a patient participation work shop was undertaken to obtain feedback around the priorities for the dementia strategy. Priorities identified and which form the basis of the Strategy' objectives and will feed into the strategy action plan include:

1. Community development including the Community Care Coordinators/community capacity and resilience building.
2. Early identification and identification of unmet need – case management
3. Education and support
4. Services working better together
5. Care homes
6. End of life

As part of Shropshire Council's transformation of Adult Social Care through the "Live Life Your Way" initiative, they have signed up to the national initiative "Making it Real (MiR)" which has been developed by family carer's and service users to assist organisations to check their progress with delivering community based support and personalisation, and to identify improvement and action planning. Shropshire Council has chosen three priorities using the MiR "I" statements to focus on for improvement of services and supporting people:

- Information and advice – having the information I need, when I need it
- Active and supportive communities – keeping friends, family and place
- Flexible integrated care and support – my support my own way

These priorities were based on service user feedback, obtained through surveys, face to face consultations and video diaries and link in with the key points raised by patient representatives at the October dementia workshop in terms of priorities for development of dementia services in Shropshire.

9.0. Delivering Shropshire's Dementia Strategy

The strategy aims to guide the commissioning plans of Shropshire CCG and Shropshire Council. By delivering the actions outlined in the plan we will be able to commission dementia services that are fit for the future.

The action plan is structured upon the seventeen outcomes identified in the National Dementia Strategy and the actions are also cross referenced to the local Health and Wellbeing board priorities for dementia; the Joint Health and Wellbeing strategy – outcomes; the Better Care Fund priorities, the Care Act 2014 and the patient representative, service users and carer's feedback.

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