



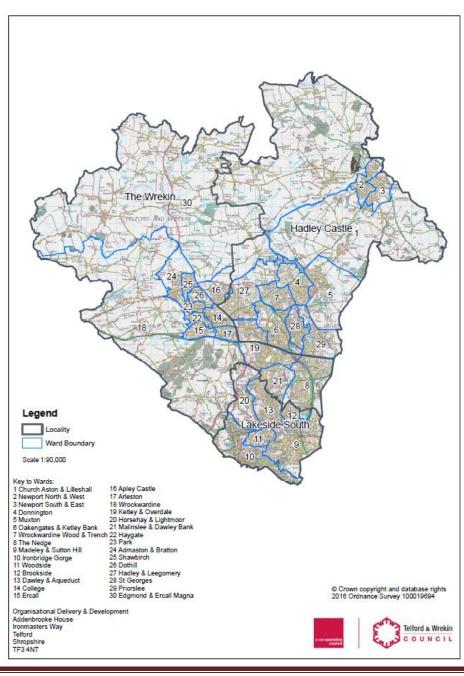


## **TELFORD and WREKIN Dementia Strategy 2016-2020**



## Telford and Wrekin Dementia Strategy 2016-2020

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## SECTION 1 SUMMARY- SHROPSHIRE, TELFORD AND WREKIN DEMENTIA STRATEGY

#### 2016-2020

#### 1 Introduction

Telford and Wrekin council and the CCG have worked together to develop this strategy to support people who live in the area who are living with dementia\* and their carers. The last joint strategy ran from 2009 until 2013 and achieved significant changes in the landscape to support people living with dementia (PLWD) and their carers. The plan achieved the following significant milestones

- A responsive memory assessment service with capacity to undertake the required assessments
- Dementia support workers in place
- Admiral nurses supporting carers
- A carers partnership board
- Health economy dementia steering group- stakeholders group across Shropshire, Telford and Wrekin
- Specialist dementia support in the local acute hospital

Work has continued to improve services to support people living with dementia and their carers. This strategy builds on the work completed locally; reviews what we have now; considers how people see the services; considers the latest evidence to support PLWD and their carers and provides a new vision for the next four years.

#### 1.1 How has this strategy been developed?

The strategy draws on a range of different information and in producing it we have asked the following questions:

- What have service users, professionals, carers, and volunteers told us about the current services, aspirations about services and what outcomes they would hope to achieve?
- What does the demographic information show us about our population needs now and how they will change in the future?
- What does the most recent evidence and research tell us about best practice?

#### 1.2 Why do we need to change?

#### 1.2.1 What local people have told us:-

Feedback from PLWD and their carers told us we are not getting it right- We were told that it isn't always easy to get a diagnosis. It can take many months to get a GP to understand there is a problem and carers find this very frustrating. Carers told us post diagnosis support is a lottery regarding what you can expect - it can be wonderful for some but frustrating and difficult for others. Reports regarding the Admiral nurse Service were very positive. We were also told that it is not always easy to know who or

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where to go for support. Carers found support groups helpful but wanted more places to go with their loved one as going without them caused more difficulty.

#### 1.2.2 Our demographic changes:-

Telford & Wrekin is an urban borough with an ageing population, with the percentage of people over the age of 80 projected to increase by 32% from 2014 to 2026. Approximately 7000 people over the age of 65 live alone in Telford, and many of these are income deprived and may be socially isolated. This would indicate we should expect more people to be living with dementia over the coming years. This number will be increased by the high levels of smoking, obesity and lack of regular exercise (which are risk factors for dementia).

#### 1.2.3 What does the research tell us that we can learn from?

Reducing the risk factors to develop dementia needs to be major element of any dementia strategy. This needs to be a key focus for Telford and Wrekin with its high level of smoking and obesity in the general population. Early diagnosis is important as some medication can be more effective in the early stages of dementia. Education programmes can support carers to understand the impact of dementia and how to manage challenging behaviours and thus helping to prevent carer breakdown. Cognitive stimulation therapy can improve the quality of life for PLWD and should be offered to all. Commissioners need to clearly defining services and then monitoring the quality and impact of the interventions, so we can improve the standard of care. (http://toolkit.modem-dementia.org.uk/database/)

#### 1.2.4 What issues do we have with our present support?

The CQC inspection (2016) highlights our local memory service as outstanding taking into consideration safety, caring, effective, responsive and well led. The only issue raised was the high caseload of the home treatment team in Telford.

The diagnosis rate for Telford and Wrekin is at 63.7% but has a target of 66.9% by April 2017.

The demand on the dementia support workers and Admiral Nurses exceeds demand. Little work has been done to support end of life care locally.

Overall cuts in funding mean there is less funding in the public sector and both commissioning organisations need to assure themselves, and the public of best value when using public funds.

## 1.3 What does this strategy aim to achieve by 2020 for people living with dementia and their carers?

To enable PLWD and their carers to say:

Me to stay me and live well, feeling secure in my communities Me and the people around me, to feel confident, informed and to know where to go when we need help'

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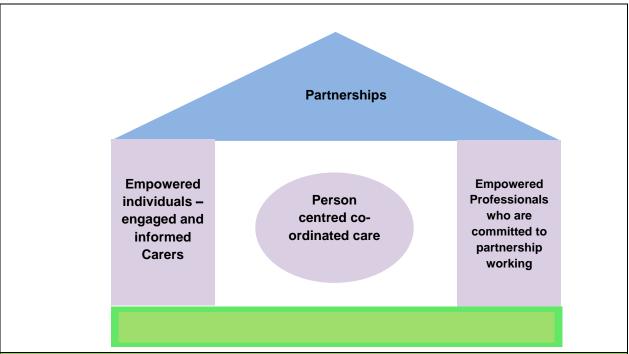
The key principles that will underpin all the work undertaken locally will:-

- Creatively build on an individual's strengths, skills and independence
- Support individuals to plan for their future
- Be honest about what can and can't be provided
- Support individuals to find someone who can help them when needed
- Ensure individuals can make timely and informed choices
- Work as one team to support individual's and their families
- With consent and when required, share an individual's story so they don't have to
- Reduce barriers to ensure individuals are able to get the help they need
- Work with individuals to find solutions to prevent a crisis
- Promote dementia friendly communities in Shropshire Telford and Wrekin
- Learn from what works well and what doesn't to improve the help what is provided.

#### 1.4 How will we make this happen?

#### 1.4.1 House of Care

We have adapted the Kings Fund 'House of Care' model to create the Telford & Wrekin House of Care which describes a whole system approach. The ethos and principles that underpin this model can help to address many of our issues and mirrors what service users and professionals have told us. The House of care provides us with a model of care that puts individuals (whether that is the person living with dementia or their carer) at the centre of all care wherever delivered



#### Supportive Communities ('The Foundations'). The model will support:

- Dementia friendly communities across the borough.
- Resilient communities where PLWD are welcomed and supported by all local networks and groups
- Increasing the role and value of the 3rd Sector to promote and develop assets in the community.

## Person-centred co-ordinated care is at the centre of the house and represents the following:

- The recognition of what is both 'important to me' and what is 'important for me'.
- Support for people living with dementia and their carers in and by their own community.
- Support for people living with dementia and their carers to become more resilient and to plan for their future.
- Support for the people living with dementia and their carers to take control of their condition and develop self-management skills as far and as long as possible.
- The inclusion of the needs of Carers.
- A relevant key worker for each person with dementia and their carer.
- Provision of tailored information (including any risks and benefits) to assist the individual to make informed decisions.

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• Support will be provided in the least restrictive environment.

### Empowered people – engaged and informed Carers ('Left Wall'). The model of care will:

- Recognise people living with dementia and their carers, as 'Expert Care Partners'.
- Encourage self care and personal responsibility where safe and appropriate to do so, along with the information, education and support to enable this to happen.
- Ensure shared decision making becomes the 'norm' where and when possible, and to plan for a time when this is not a reality
- Use digital and assistive technologies to empower and support people where possible and reduce duplication.
- Provide Personal budgets where appropriate to support people to have more control over their life.

## Empowered Professionals who are committed to partnership working ('Right Wall'). The model will ensure that:

- There will be a culture embedded across the workforce that promotes shared decision making, self-management and wellbeing of people living with dementia and their carers.
- Services will be integrated through multidisciplinary working with the voluntary and charitable sector playing key roles.
- Professionals at all levels will have the right competencies, capability and capacity to do their jobs to the highest standards.
- Professionals discuss the relevant risks of treatment/care with people living with dementia and their carers and support them with the decisions they make.
- Professionals will understand their local communities, use local assets to support people living with dementia and their carers and collaborate with the community to bridge any gaps.

We will use partnerships as an enable to achieve our aspirations:-

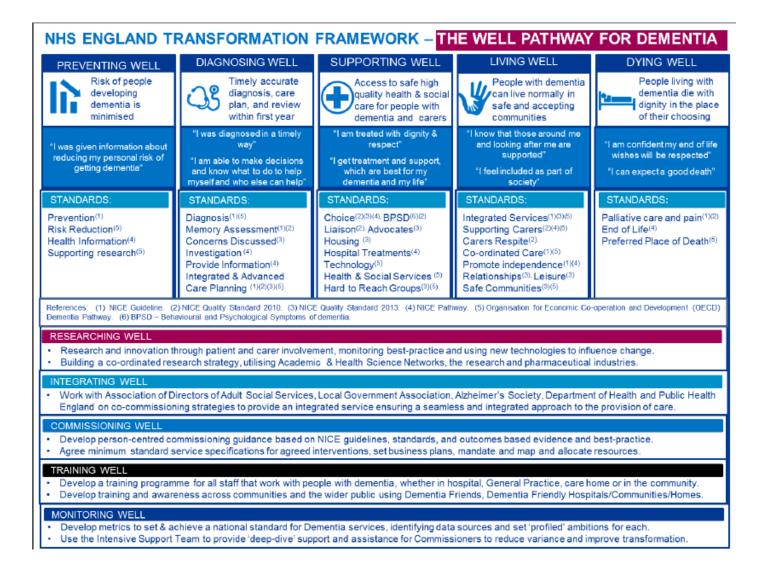
#### Partnerships including Joint Commissioning ('The Roof')

- We will work across local authority, NHS, other statutory organisations, voluntary sector, private sector and employers to ensure a joined up approach.
- We will include people living with dementia and carers in every stage of the commissioning cycle.
- We will explore opportunities for joint commissioning.
- We will focus on Social Value when undertaking commissioning.
- We will commission services on outcomes, including those identified by people living with dementia and their carers.
- We will ensure a robust voluntary sector in the borough.
- We will ensure that where possible there are systems that talk to each other to reduce bureaucracy and duplication and assist with record sharing.
- We will ensure service specifications include the delivery of shared decision making with service users.
- We will ensure soft intelligence; compliments and complaints inform commissioning decisions.

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#### 1.4.2 The Action Plan

NHS England has developed a 5-year transformation implementation plan called the `Well Pathway for Dementia` which covers preventing well, living well, supporting well and dying well. The plan supports the Prime Ministers challenge 2020. This plan will support the implementation of the vision for the Dementia strategy across the Shropshire Telford and Wrekin footprint and is based on this well pathway.



#### 1.4.3 Governance

Five work streams have been set up to take forward the work of the footprint. Each is led by either a person living with dementia, third sector or commissioner. These will be subgroups of the Health Economy Dementia Steering Group(HEDSG). The subgroups shall agree a model and then prioritise workload. The HEDSG will monitor the work and feedback to the Health and wellbeing Boards.

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#### **SECTION 2 REVIEW OF DEMENTIA SERVICES**

#### 2 What is dementia and what is its impact?

#### 2.1 What is dementia?

Dementia is a progressive condition, which means that the symptoms become more severe over time. People with dementia and their families have to cope with changing abilities such as the capacity to make decisions. Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years. Dementia can start before the age of 65, presenting different issues for the person affected, their carer and their family. People with young onset dementia are more likely to have active family responsibilities – such as children in education or dependent parents – and are more likely to need and want an active working life and income. Family members are more frequently in the position of becoming both the sole income earner, as well as trying to ensure that the person with young onset dementia is appropriately supported. The reality for many people with dementia is that they will have complex needs compounded by a range of co-morbidities. A recent survey by Alzheimer's Society found that 72 per cent of respondents were living with another medical condition or disability as well as dementia. The range of conditions varied considerably, but the most common ones were arthritis, hearing problems, heart disease or a physical disability.

#### 2.2 How can it be treated?

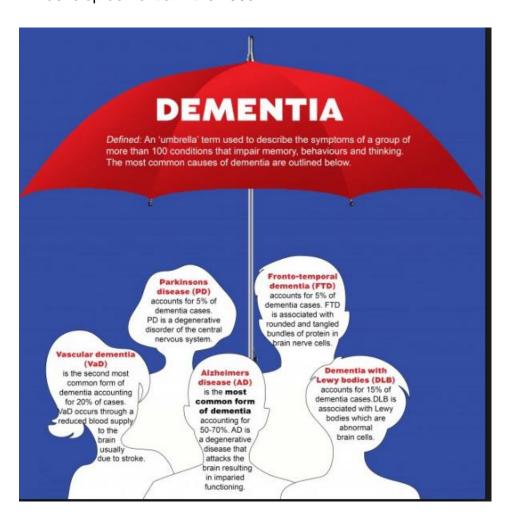
Currently, dementia is not curable. However, medicines and other interventions can lessen symptoms for a period of time and people may live with their dementia for many years after diagnosis. There is also evidence that more can be done to delay the onset of dementia by reducing risk factors and living a healthier lifestyle. There is also a great deal that can be done to help people with dementia at earlier stages. If diagnosed in a timely way, people with dementia and their carers can receive the treatment, care and support (social, emotional and psychological, as well as pharmacological) to enable them to better manage the condition and its impact. For example, there is much that can be done to help prevent and ameliorate symptoms such as agitation, confusion and depression. Advanced dementia can be very difficult for the individual and their family and it is not always possible at this late stage of the condition to 'live well', but compassionate treatment, care and support throughout the progression of the condition is essential to enable people with dementia to one day 'die well'.

#### 2.3 How many people are living with dementia?

Estimating the prevalence of dementia in England is not an exact science. The Delphi approach is a consensus statement based on experts reviewing a series of international studies whereas the Cognitive Function and Ageing II Study (CFAS II) uses real data from three populations in England, allowing for more granular estimates of prevalence, for example at Clinical Commissioning Group level, and indicates that

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there are ranges. People with learning disabilities have an increased risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s.



#### 2.4 What is the impact of Dementia?

The Alzheimer's Society Dementia 2014 survey reported that 40 per cent of people with dementia felt lonely and 34 per cent do not feel part of their community. There is a similar impact on the carer.

#### Hospital care

People with dementia are sometimes in hospital for conditions for which, were it not for the presence of dementia, they would not need to be admitted. An estimated 25 percent of hospital beds are occupied by people with dementia. People admitted to hospital who also have dementia stay in hospital for longer, are more likely to be readmitted and more likely to die than patients without dementia who are admitted for the same reason.

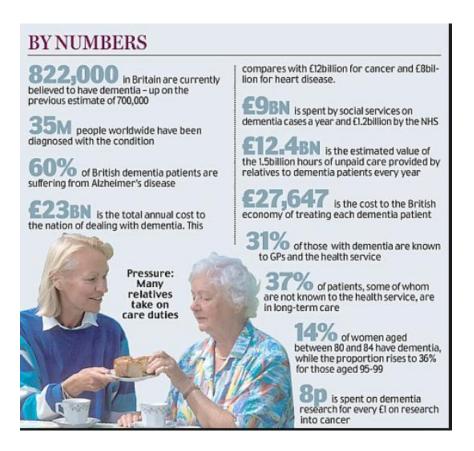
#### Care homes and care at home

An estimated one-third of people with dementia live in residential care and twothirds live at home.

Approximately 69 per cent of care home residents are currently estimated to have dementia<sup>21</sup>.

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People with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than similar people without dementia.



#### Costs

The total annual cost per person with dementia in different settings is estimated as follows: People in the community with mild dementia £25,723 People in the community with moderate dementia £42,841 People in the community with severe dementia £55,197 People in care homes with dementia £36,738. Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007). Of these, one-third live alone in their own homes (Mirando-Costillo et al, 2010). The UK Homecare Association estimate that 60% of people receiving care at home have a form of dementia (UKHCA, 2013). Unpaid carers save the state £11 billion per year.

#### **SECTION 3 REVIEW OF DEMENTIA SERVICES 2016-2020**

#### 3 Commissioning, contracting and Investment

#### 3.1 Commissioning responsibilities

- 3.1.1 The Clinical Commissioning Group (CCG) is responsible for commissioning specialist health provision provided including assessments and diagnosis services, post diagnosis support, support in a crisis in both acute and community settings. In addition it commissions generalist services that people living with dementia also access.
- 3.1.2 The Local Authority (LA) commissions and provides adult social care services as part of its statutory obligations under the Care Act, Mental Health Act and Mental Capacity Act. This includes commissioning services which promote wellbeing; reduce ill health and dependency; Advocacy; supporting carers; care packages and supported living.

#### 3.2 Contracting

- 3.2.1 The main CCG contract is held by an NHS provider (South Staffordshire and Shropshire Foundation Trust). The CCG holds smaller contracts through the grant process to support PLWD and carers.
- 3.2.2 The LA commission a variety of providers ranging from large charitable organisations to small local private providers.

#### 3.2.3 Contract monitoring:-

Both organisations have robust and regular contract monitoring processes in place to monitor spend and performance of its providers. The CCG has a quality monitoring process where quality and outcomes of services are monitored on a monthly basis. Quality Assurance processes are in place in the LA to ensure outcomes are delivered.

#### 3.3 Investment

The spend on dedicated Dementia services across Telford and Wrekin CCG is £2.7M. Prescribing costs for dementia related drugs in the CCG are £98K.

#### 3.3.1 Spend by organisation

Commissioner	Budget 2015 / 16 £000	Comments				
ccg	£6,889.094	This is not an exact breakdown as the main element is part of a block contract and other contracts include spend on all older adults and				
		Dementia spend cannot be identified				
LA	£11,540,866	This includes spend on all older adults and Dementia spend cannot be identified				
Total	£18,429,960					

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#### 3.3.2 Spend by contract type (CCG)

Contract type	Budget 2015 / 16 £000	Number of providers	Comments
Cost and Volume	£2,411,686	1	South Staffordshire and Shropshire Foundation Trust (SSSFT)
Block contract	£88,450	1	Shropshire community for Admiral nurses
Individual packages	£4,227,688	273	273 patients over the age of 65 currently have in a service commissioned by the complex care team
Grant	£110,00	2	Dementia advisors and support groups
Grant	£21,270	1	Dementia worker

#### 3.3.3 Spend by contract type (LA)

Contract type	Budget 2015 / 16	Number of Providers	Comments
Spot purchase	£4,867,969	Not known (Residential – 100 ongoing clients, nursing – 60 ongoing clients)	Nursing and residential EMI 2015/16 spend
	£164,796		Day care for older people*
	£648,319		Direct Payments for older people*
	£4,254,981		Homecare for older people*
Block	£1,604,801	2	Nursing and residential EMI 2015/16 spend

#### Other

Our 2013/14 data tells us that at that time there were:

- 63 homecare providers operating in Telford and Wrekin, of these 14% offered a service to those with dementia. At that time just 2% of all homecare services were contracted via a block contract, all other homecare was spot purchased
- 10 daycare providers operating in Telford and Wrekin, of these 15% offered a service to those with dementia. At that time 17% of days purchased were contracted via a block contract, all other daycare was spot purchased

#### 3.3.4 Public Health contribution to promoting mental wellbeing

Public Health (Part of the LA) funds a large range of services which provide a preventative approach to ensure people to stay as healthy as possible. Many of the interventions will be focused on improving or maintaining health and increasing activity. This budget is for population approaches and covers lifestyle interventions for all age groups and conditions.

<sup>\*</sup>Spend specifically on EMI residents not available

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#### 3.3.5 Carers Funding

The LA and CCG pool budgets to support carers. The total carers pooled budget is £ 515.500. This is not specific funding for dementia carer support. It is not possible to calculate the % of care that is supporting those living with dementia. The funding covers a range of support including the provision of a Joint Carers Commissioning Officer which is central to driving forward the local carer agenda, Emergency Response Service, Carers Respite and a range of workshops which focus on promoting well being and carer resilience.

#### 3.4 Distribution of funding

Investment from both organisations is focused on the highest cost and highest risk patients. These are service users who require hospital admission and social care packages to support them in activities of daily living.

#### 3.5 Challenges

#### 3.5.1 Financial

Both organisations are experiencing significant financial challenges with an increase in the populations' expectations of service provision; the demographic changes; national policy imperatives and reduced budgets.

#### 3.5.2 Systems and Processes

There is no forum to discuss the contracts held across the economy as they impact on each other. Changes in one contract may have a knock on effect on another organisation. Both organisations have their own systems and processes for managing complex service users and contracts.

#### 3.5.3 Benchmarking spend on Dementia

#### 3.5.3.1 CCG

NHS benchmarking on health spend is complex. Programme budgeting has been used to benchmark CCGs against investment in specific disease areas but has significant problems setting the baseline for comparisons. In addition it does not differentiate dementia spends from mental health and therefore cannot be determined.

#### 3.5.3.2 LA Benchmarking Data –

The local authority spend on a variety of the needs of the population and spend on dementia is not straightforward to extract. The authority often identify spend in relation to individuals or client groups e.g. older people, learning disabilities, mental health and someone with dementia may also have other conditions and so it is more difficult to extract spend on dementia specifically. However, we have commissioned some of our provision from nursing, residential, domiciliary care agencies, day opportunities who may specialise in supporting individuals with dementia and where possible we do identify commissioned spend. (See Spend by Contract Type).

As an authority we are also promoting personalisation and where appropriate we are enabling individuals and carers to have their own choice of purchasing rather than be limited to commissioned service provision which may also affect the monitoring of spend specifically on dementia.

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#### 3.6 What does this mean for the vision?

The main issues are:

- Opportunities to commission services jointly to improve integration and value for money should be considered
- Pressures from austerity need to lead to innovative ways to provide services and develop more community resilience.
- Increasing spend on prevention and lower level treatments may reduce the more expensive interventions in the future.
- Need to consider the development of pooled budgets

#### **SECTION 4 REVIEW OF DEMENTIA SERVICES**

#### 4 Current dementia services

#### 4.1 Introduction

This chapter describes the services that support People living with Dementia (PLWD) in Telford and Wrekin in 2015 and how we benchmark against national outcomes.

#### 4.2 Service provision

#### 4.2.1 Health

Specialist Dementia services are in the main provided by South Staffordshire and Shropshire Foundation Trust (SSSFT) and the local authority. The Trust provides diagnostic, community services and inpatient services. General health services are provided by the local GP practices (20?) and the local hospital Princess Royal (part of Shropshire and Telford Hospitals). Community care (nursing including Admiral nursing, therapy) are provided by Shropshire community trust

#### 4.2.1.1 Assessment and Diagnostic service

The service provides assessment in local GP surgeries as well as the trust facilities and service users own homes. People are seen on average within 2 weeks of referral to start to the assessment process. The service is staffed by Consultant Psychiatrists, Psychologists, Nurses, Occupational Therapists and Support workers. Prior to assessment the team ensures physical health checks have been completed. The assessment process involves pre-diagnostic counselling, informed consent about the assessment and information sharing, as well as the process of clinical history taking and analysis. Information regarding risk reduction with regards to dementia is given. Appropriate referrals are made for CT and SPECT scans.

#### 4.2.1.2 Community support post diagnosis

Post diagnostic support involves the commencement of medication, where appropriate and following the necessary ECGs and blood tests. Information is shared with regards to helping to understand the illness and manage some of the symptoms, getting peer support from voluntary agencies, other carers and service users and planning for the future decision making. Cognitive Stimulation Therapy (CST) reminiscence therapy, individual psychotherapy and neuropsychological testing is provided by the service. A home treatment team provides intensive support at times of increased need. Those on medication are monitored in line with NICE Guidance and reviewed accordingly.

#### 4.2.1.3 In patient services

Specialist dementia Inpatient beds are provided at Redwoods hospital in Shrewsbury. There is one ward dedicated to older age adults which mainly caters for those people living with Dementia. 31 people from Telford and Wrekin were admitted in 2015/16 utilising 1673 bed days with an average of 54 day stay.

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In addition PLWD are also admitted to the local acute hospital when they have physical health problems. The RAID team commissioned from SSSFT provide support to PLWD in both the Emergency Department and ward environments. They are able to screen people in those environments where there are concerns regarding memory loss and to offer advice and support where behaviours are more difficult to manage. The acute hospital has staff that screen older people for memory problems and an advanced nurse practitioner to support staff who manage PLWD in the hospitals.

#### 4.2.1.4 Admiral Nurses

The CCG and local authority commission Admiral nurses to support carers of people living with dementia. There are two whole time equivalent employed through Shropshire Community trust with a third part time worker funded non recurrently. Referrals are taken by the team and these come from other service providers and self referrals. They hold caseloads of up to 60 people and case load is managed in the following way:

- Intensive support: One to One work for a targeted amount of time
- Moderate support: Regular support via face to face or telephone calls
- Holding: Carers contact the service when needs change and review is required

#### 4.2.1.5 Post diagnosis support

This is provided by Alzheimer's Society and Age UK through a grant mechanism. The grant funds the Alzheimer's Society to provide three part time dementia support workers (1.5FTE) who provide 1:1 emotional and practical support to PLWD (diagnosed and carers), this includes coping strategies when PWD exhibit early stages of changing behaviours. On top of this additional hours currently provide a weekly Singing for the Brain group in Telford and two monthly peer support (for carers) & activity groups (for PWD) in Newport and Wellington. Alzheimer's Society provide regular education and training programmes across T&W which are funded by the Council. Age UK receive funding from the CCG towards the delivery of a number of Diamond Drop In Cafes which aim to reduce social isolation for PLWD. There are 4 of these, three of which operate on a fortnightly basis and one is monthly.

#### 4.2.2 Social care commissioned services

The Care Act 2014 is being implemented by the Council which also impacts on how we commission more actively in commissioning for better outcomes in order to promote wellbeing and prevent, reduce and delay the deterioration of individuals and to assist carers and individuals to be supported having the right help, at the right time to live well and be supported well in their own homes as much as possible.

#### 4.2.2.1 Information, Advice and Advocacy

The Council has taken into account the requirement for easier access to information and advice and in response has developed an 'Information Advice Strategy' which includes an electronic form of the collation of Information and Advice 'My Life' a web portal - http://www.telford.gov.uk.

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The Council have recognised that some groups of the population to include carers and those people living with dementia may wish to talk to an individual rather than Internet access. As a result, from 1<sup>st</sup> October 2015, the Council has commissioned a consortium of the voluntary sector to provide an Information, Advice and Advocacy Service (My Choice). This service provides a single telephone access point for both carers and those living with dementia to seek more specialised support.

#### 4.2.2.2 Personalisation- Choice and Control

We are supporting people to ensure that the people requiring longer term care can take as much control over their lives as their needs allow. We are working with the CCG and a variety of groups to include membership of Dementia Action Alliance to enable people to live well with dementia and going forward in development of this strategy identify community based services to include day opportunity venues e.g Older People Enjoying Life Centres which assist in meeting the challenges of social isolation and social exclusion in understanding the requirements of those living with dementia and their carers as respite opportunities as well as services that enable people with dementia to take more control over their own lives and have links to the community.

#### 4.2.2.3 Community Based Solutions

To assist people gaining the right help, at the right time and promoting independence, we have a selection of the care and support market that specialise in providing personal care and support services. We also have a specialist sector that provide services to people living with dementia that are very aware of the complexities of the condition and provide a sensitive service. We are aiming to help people continue to live in their neighbourhood and community, where this is feasible and affordable. We do commission a selection of nursing and residential provision across Telford and Wrekin. As we go forward residential care may only be explored where other options have been exhausted and have found that this is the only way to meet someone's care and support needs in a safe way.

We are supporting the person to safely meet their assessed needs in a community based setting and promoting independence in the person's own home and assisting resilience for carers together with carers commissioned services. Services may include arts and culture, to assist in living with dementia is supported as sensitively as possible with the individual at the heart of the provision.

Technology is developing rapidly, and we are ensuring that the interventions we offer people will focus on how we can promote their independence. This means we will always seek to use community based solutions including assistive technology and adaptations in the home, where these will enable people to remain safe and meet their care needs.

#### 4.2.3 Other Commissioning

#### 4.2.3.1 Public health commissioning

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Also sits within the local authority and commissions a range of interventions including supporting healthy lifestyles.

#### 4.2.3.2 Carers support-

It is the identification and raising awareness of carers across Telford and Wrekin community which requires particular focus with a continued emphasis on prevention, promoting self help and ensuring a range of solutions are employed at an earlier stage in their caring lives in line with the Right Help, Right Time pathway which focuses on prevention and development of carer resilience.

Through the Prevention and Well Being Strategy, a collaborative approach requires everyone to be mindful of the emotional, physical and mental impact of caring. The Care Act 2014. At present the support provided is:-

- All ages Carers Information, Advice and Support Service where Carer Assessments are undertaken
- Emergency Carers Response Service providing replacement support for family carers in Crisis
- Moving and Handling Family Carer Adviser providing bespoke safe moving techniques in the family home.
- A range of workshops: Cookery, Creative: Arts/Painting/Drawing/Craft/Singing and Pottery where carers have time for themselves and receive peer support.
- Personalised Carer Support: Targeted support to give carers respite
- Pamper Sessions which focus on well being in conjunction with Health Trainers
- Specialised Dementia Workshops for family carers focussing on understanding dementia, managing stress, life planning
- Friend and Family Service providing support to those living with someone who has a drink or drug addiction
- Relationship Support for carers who are experiencing loss or finding change or relationships difficult to manage

The Carers Partnership Board is linked to the Health and Well Being Board and it provides an opportunity to influence service design promoting collaborative practices between carers, commissioners, voluntary organisations and statutory organisation.

#### 4.3 Benchmarking of NHS services

The following tables are taken from the Public health profile fingertips. :- http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia
These profiles provide a rich source of data across a range of health and social care data to support commissioning.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

#### 4.3.1 Prevalence Compared with benchmark: Lower Similar Higher Not compared \* a note is attached to the value, hover over to see more details Export table as image **Telford and Wrekir** Stoke-on-Trent Warwickshire Walsall Indicator Period Dementia: Recorded prevalence 2014/15 ( ) 0.74 0.76 0.78 1.06 0.78 0.79 0.79 0.77 0.76 0.82 0.79

4.34

4.61

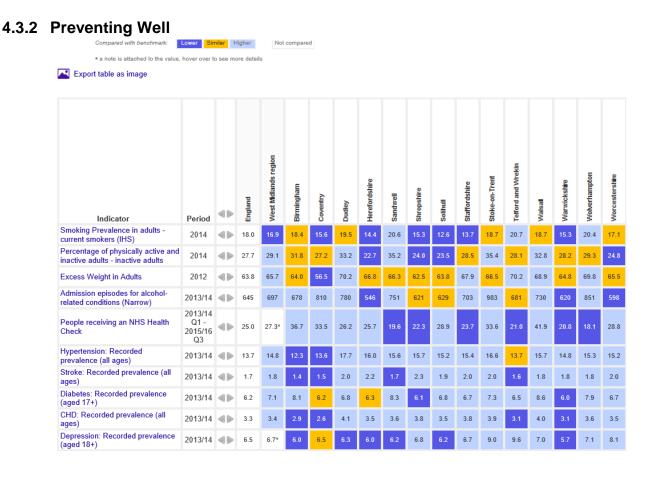
4.47

This indicates that Telford and Wrekin is below the national figure for recorded prevalence which is a key area for the strategy to work on.

**4.27 4.10**\*

Dementia: Recorded prevalence

(aged 65+)



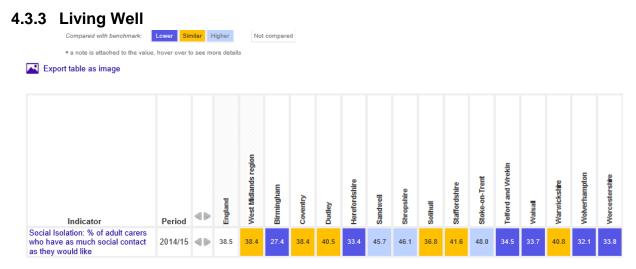
Telford and Wrekin has a mix of indicators that are either better or worse than the national figures. The strategy needs to ensure there is a focus on areas where we are poorly performing these include:-

- Smoking prevalence
- Obesity in adults
- The number of people receiving NHS health checks
- Management of diabetes

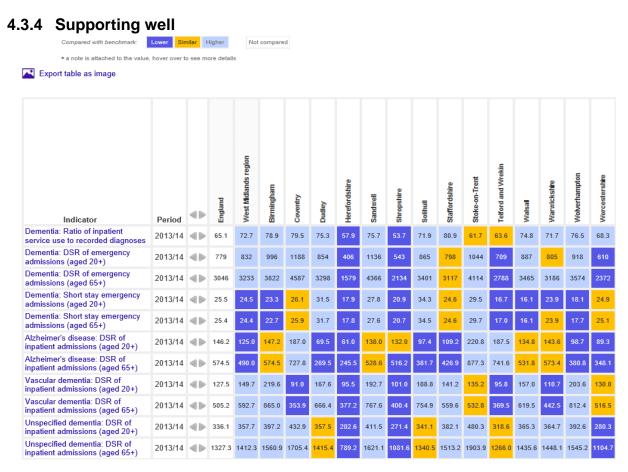
<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

*Dementia throughout th	is document is used	to describe a sym	nptom of a range of	f diseases

• Support for people who are depressed



Telford and Wrekin has a lower % of adult carers who have as much social contact as they would like so a key area for community development



Another mixture of good and not so good indicators for Telford and Wrekin. The action plan needs to focus on the following:

Data for people living with dmentia who are admitted into an acute hospital- this
needs reveiwing as we are higher for Alzhermeirs admsions but lower for
vascular dementia.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

# 4.3.5 Dying Well Compared with benchmark: Lower Similar Higher Not compared \* a note is attached to the value, hover over to see more details Export table as image

Indicator	Period	<b>4</b> ▶	England	West Midlands region	Birmingham	Coveritry	Dudley	Herefordshire	Sandwell	Shropshire	Solihull	Staffordshire	Stoke-on-Trent	Telford and Wrekin	Walsall	Warwickshire	Wolverhampton	Worcestershire
Directly Age-Standardised Rate of Mortality: People with dementia aged 20+	2013	<b>●</b>	187.2	194.6	193.7	188.8	190.1	154.9	237.3	177.0	167.4	210.6	220.2	194.1	176.6	183.6	235.9	190.6
Directly Age Standardised Rate of Mortality: People with dementia aged 65+	2013	<b>●</b>	746	776	774	756	758	619	946	703	662	839	877	775	702	730	942	761
Deaths in Usual Place of Residence: People with dementia aged 65+	2013	<	66.6	62.5	56.2	64.3	64.9	70.5	54.5	74.1	58.2	63.0	62.0	68.9	51.6	63.6	49.9	72.9
Place of death - care home: People with dementia aged 65+	2013	< ▶	58.6	54.4	46.8	56.6	58.0	62.2	43.2	67.4	48.5	56.3	56.3	59.9	40.2	55.3	42.4	65.6
Place of death - hospital: People with dementia aged 65+	2013	< ▶	32.6	37.3	43.8	36.0	34.9	29.6	44.9	24.1	41.4	37.3	36.5	30.8	47.7	36.7	50.5	26.9
Place of death - home: People with dementia aged 65+	2013	<b>●</b>	7.4	7.3	8.4	7.1	6.4	7.5	10.4	6.2	8.8	5.6	4.8	8.1	10.6	7.6	6.9	6.6

Telford and Wrekin benchmarks similar to England across all indicators

#### 4.4 Governance

Oversight of the action plans and services to support PLWD is undertaken across Shropshire and Telford and Wrekin by the health economy dementia steering group (HEDSG). This is a group of stakeholders including PLWD. It brings providers together and is a forum for sharing information about services to support PLWD and their carers.

#### 4.5 What does this mean for the strategy?

- Need to focus on increasing the numbers of patients diagnosed to ensure they get early treatment and support
- We need to focus on the lifestyle issues of smoking and obesity to reduce the risk for future generations and to increase NHS Health checks
- We need to facilitate the building supportive communities that support carers and PLWD, so they feel more included and have the social contact they would wish.
- We need to ensure we understand the data for hospital admission for other health related conditions in the acute general hospitals.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

#### **SECTION 5 REVIEW OF DEMENTIA SERVICES**

#### 5 Engagement

#### 5.1 Introduction

This section describes the work undertaken at both national and local level to understand the messages form PLWD and their cares. In addition it describes the engagement with local clinicians and their views of the services we have and the services we should provide.

#### 5.2 National

#### 5.2.1 Outcomes - Dementia Action Alliance

In 2010, Alzheimer's Society worked with partner organisations to launch a National Dementia Declaration for England. This was developed by the Dementia Action Alliance (DAA), which brings together different organisations in England interested in delivering change. In the Declaration, people with dementia and carers described seven outcomes that are most important to their quality of life, many of which echo common themes from other research.

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carer's needs.
- I have support that helps me live my life.
- I have the knowledge to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I am confident in my end of life wishes will be respected. I can expect a good death.
  - I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.

#### 5.3 Local process for engagement.

Local support groups where both PLWD and their cares have been attended. In addition one individual living with dementia also provided a view on the support and services available in the locality.

#### 5.3.1 Feedback with service users and carers

Themes from the local engagement were:-

- Waiting times Took years to get diagnosis- 2-3 years for some people. Some waited for assessment appointment when were staff off sick. Waiting list for admiral nurses
- Quality of services- 6 monthly reviews just repeat of tests to see how
  deteriorated no other support. Some PLWD were assessed and reassessedgot use to the questions and could answer them easily. No support for a PLWD
  who wasn't sleeping- just brushed off. Other behaviour problems not really

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- helped by Memory service- these were experienced carers and had tried most techniques needed more help/advice
- Equity of services-Service patchy- seems to depend on the clinicians involved in memory service. Luck of the draw what service you get
- Post diagnosis support-Some groups for carers can't take PLWD- need someone to sit or take them with them. Some PLWD wont accept anyone coming into their home-why cant they attend these groups. Nothing for a previous active man who doesn't like painting poetry etc. Still some discrimination re dementia- some local groups don't want PLD in their groups as they are too distributive

#### 5.3.2 Feedback from Clinicians

GPs discussed dementia and the support services at the GP forum. They also felt there were problems with diagnosis especially for those with early stages of dementia or with Mild Cognitive Impairment. They felt that more support in the patient's own home earlier would be helpful with pre assessment being undertaken in the home. They wanted clear pathways with responsibilities for tests and diagnosis in place and structured post diagnosis support. They felt there need to be improved communications with services and the GP as the GP has to manage other clinical conditions of the patient. GPS wanted seamless support for patients particular in a crisis including out of hours support. Feedback regarding the Admiral Nurse Service was again positive with requests to increase the service.

#### 5.4 Key items for the strategy

- Develop a clear referral pathway into the memory service with waiting time targets
- Develop an Mild Cognitive Impairment pathway
- Ensure crisis services are available across service providers
- Develop an equitable service for all people living with dementia that supports them when required
- Develop a model of dementia care that supports the above.
- Consider the range of support services in place to ensure both the PLWD and the carer is supported at the same time.

#### **SECTION 6 - REVIEW OF DEMENTIA SERVICES**

#### 6 The evidence base

#### 6.1 Introduction

This paper describes an overview of national documents that are available to support the development of a local strategy and relevant quality standards that need to be considered.

#### 6.2 Prime Minsters challenge 2012

In 2012 the PMs Challenge was published. It focused on three key areas:-

- · Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

This challenge has recently been updated. It sets out what this government wants to see in place by 2020 in order for England to be:

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live
- The best place in the world to undertake research into dementia and other neurodegenerative diseases

It focuses on developing dementia friendly communities; providing early diagnosis; supporting people with information and choices; ensuring staff have an understandings of dementia and the needs of those living with dementia, and developing more research opportunities.

#### 6.3 Five year forward view (2014)

There are three main themes in the 5 year forward plan- an ambition to improve quality; a greater focus on prevention and engaging communities. The focus on prevention includes the prevention of both physical and mental health problems. It also includes the promotion of employment which may affect those people with early onset dementia.

In addition the Five year Forward plan promotes engaging communities by increasing partnerships with charitable and third sector and by increasing and supporting volunteering. The Council and NHS locally need to ensure they are exemplar employers in promoting good mental health with their staff.

#### 6.4 Dementia 2014: Opportunity for change- September 2014

People with dementia are frequent users of health and social care services. A quarter of hospital beds (Alzheimer's Society, 2009) and up to 70% of places in care homes are occupied by people with dementia (Alzheimer's Society, 2014a), and over 60% of people receiving homecare services have dementia (UKHCA, 2013). Unprecedented

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cuts to the care system and unco-ordinated reforms are leaving many people without access to the vital support they need to live well. Demand for services is increasing, as spend on social care in parts of the UK decreases (ADASS, 2014).

People with dementia and family carers can live well if they have access to good quality, integrated care that is affordable, and if they live in a housing environment that meets their needs. The rising cost of dementia to society can be attributed to the failure of our current health and social care services to appropriately deliver these requirements. Our survey found that fewer than one in five people thought they received enough support from the government. The gap is being filled by unpaid carers who are keeping the system afloat (Alzheimer's Society, 2014a). Action point's from the document are:-

**Action 1**: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017

**Action 2**: Twelve weeks from referral to diagnosis

**Action 3**: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers

**Action 4**: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland

**Action 5:** An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia

**Action 6**: A fully integrated health and social care system that puts the needs of people first

**Action 7**: People with dementia and their carers must be involved in the commissioning, design and development of services

**Action 8**: High-quality mandatory training for all staff providing formal care to people with dementia

**Action 9:** All communities to become more dementia friendly

**Action 10**: Everyone should have improved awareness of dementia

**Action 11**: All businesses and organisations to take steps towards becoming dementia friendly

**Action 12**: Dementia research should receive a level of investment that matches the economic and human cost of the condition

**Action 13**: All people with dementia and carers should have access to the best evidence-based care and research

**Action 14**: People affected by dementia and their carers should be given greater opportunity to participate in dementia research

#### 6.5 NICE guidance

NICE produces pathways, guidelines and quality standards to support the commissioning of dementia services. These are based on evidence and should be the basis for services specification development and delivery. Pathways include dementia diagnosis and assessment and treatment interventions.

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#### NICE -Quality statements for people living with dementia

- Statement 1. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
- Statement 2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- Statement 3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change
- Statement 4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
- Statement 5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
- Statement 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
- Statement 7. People with dementia live in housing that meets their specific needs.
- Statement 8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
- Statement 9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
- Statement 10. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.
- Other quality standards that should also be considered when commissioning and providing a high-quality service are listed in Related NICE quality standards.

#### 6.6 Other documents

Over the past few years several documents and initiatives have highlighted the importance of the service users experience and the need to focus on improving these experiences where possible.

Lord Darzi's report 'High quality care for all' (2008) highlighted the importance
of the entire service user experience within the NHS, ensuring people are
treated with compassion, dignity and respect within a clean, safe and wellmanaged environment.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

- The NHS Constitution (2013) describes the purpose, principles and values of the NHS and illustrates what staff, service users and the public can expect from the service. Since the Health Act came into force in January 2010, service providers and commissioners of NHS care have had a legal obligation to take the Constitution into account in all their decisions and actions.
- The King's Fund charitable foundation has developed a comprehensive policy resource – 'Seeing the person in the patient: the point of care review paper' (2008).

#### 6.7 What does this mean for the strategy?

- People living with dementia and their carers need to be involved at every stage of the development of the strategy and the services that are commissioned
- The prevention agenda must be considered within the action plan
- High quality training needs to be in place for all staff
- Communities need to be strengthen to support PLWD and their carers
- Services commissioned need to deliver quality standards.

#### **SECTION 7- REVIEW OF DEMENTIA SERVICES**

#### 7 Demographic profile

#### 7.1 Introduction

This paper describes a summary of the local demographic data for Telford and Wrekin. In addition it describes the different populations the two organisations commission.

#### 7.2 Commissioning populations

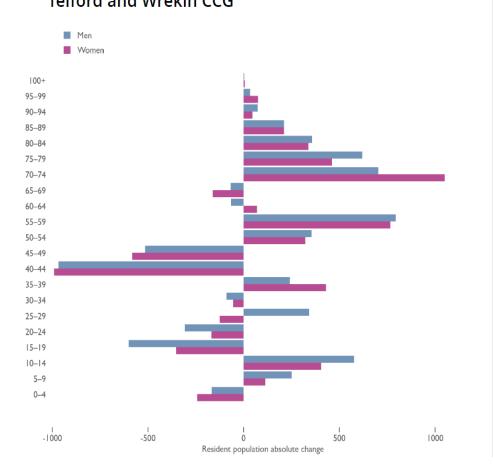
This is joint strategy but the two organisations commission services on a different footprint. The local authority commission's services for people who live in the borough whilst the CCG commissions services for people registered with a GP in the organisation. The population of the borough is 166,641 whilst for the CCG it is 178,412.

#### 7.3 General data

The 2011 Census population of Telford and Wrekin was recorded as 166,641 an increase of 5.2% from 2001. This strategy focuses on the adult population which in 2014 was approximately 136,000.

The age profile in Telford & Wrekin is changing, with the older age groups increasing most rapidly.

## Resident population absolute change by age group, 2014-2019 Telford and Wrekin CCG



#### Sources:

Ons.gov.uk, (2015). Annual Small Area Population Estimates, 2013 - ONS. [online] Available at: http://www.ons.gov.uk/ons/rel/sape/small-area-population-estimates/mid-2013/mid-2013-small-area-population-estimates-statistical-bulletin.html#tab-Clinical-Commissioning-Group-Population-Estimates [Accessed 3 Sep. 2015].

Ons.gov.uk, (2015). 2012-based Subnational Population Projections for England - ONS. [online] Available at:

http://www.ons.gov.uk/ons/rel/snpp/subnational-population-projections/2012-basedprojections/stb-2012-based-snpp.html [Accessed 3 Sep. 2015].

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

#### 7.4 Demographics for older people compared to England

Population	Telford	England	What does this mean for us?
1 opulation	and	Lingiana	What does this mean for ds:
	Wrekin		
Over 65 year olds	14.5% to	16.4%	7,113 are living alone. We have
ever so year side	total	, .	less older people in our
	population		community than England but this
			will increase
Households where all	18.5%	20.7%	Lower than England average
residents are over 65			
Income deprived	21.7%	18.1%	As above
households over 60			
years			
	ed Future Po	pulation cl	nanges from 2011
65-79 year olds	+19%	2016	This will increase the numbers of
			PLWD
0ver 80 year olds	+32%	2016	As above
18-64 year olds	+5%	2020	Smaller growth in adult population
			to support older people
		Ethnicity	
BME	10.5%	20.2%	Much lower than England figure
			but rising and may rise more
			quickly with increases in asylum
			seekers.
		orted healt	
Reporting bad health	18.1%	15.3%	4,400 over 65 year olds say their
age over 65 years ( self			health is bad or very bad- whilst
reported)			we have lower numbers they are
			reporting more bad health- need
			to consider the impact of dementia
			and caring
Life expectancy	81.7	82.8	
Females	years	years	
Life expectancy males	77.7	78.9	
	years	years	

This indicates that whilst we have lower numbers of older people in Telford and Wrekin as a % of the total population we have a greater number living in income deprived households and more reporting to be in bad health. These issues need to be considered as it is likely to make it more difficult for the PLWD and their carers to cope with the impact of the disease.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

#### **Dementia Profile Data**

#### 3.10 People with Dementia (Estimated Prevalence)

Table 11: Estimated number of people with dementia

Locality	Area	Under 65 (early onset dementia)	65-74	75-84	85+
		ŧ	ŧ	ŧ	ŧ
	Donnington	-	25	75	75
Hadley Castle	Hadley	-	25	25	25
ប៉ី	Newport	-	50	100	125
le.	Oakengates & St Georges	-	50	100	100
Ĕ	Area Total	25	125	300	325
£	Brookside	-	-	25	25
Lakeside South	Dawley	-	25	50	50
e e	Sutton Hill	-	25	50	50
esi	Woodside	-	25	25	25
Ž	Area Total	-	75	150	150
	Arleston	-	25	75	75
_=	Malinslee	-	25	50	25
Wrekin	Newdale	-	-	-	-
>	Wellington	-	50	100	100
Ę	Area Total	25	100	225	225
Telford and W	/rekin	50	300	675	700

Source: Prevalence rates have been applied to ONS Mid-year population estimates for age groups, all numbers have been rounded to the nearest 25

The ONS mid year poulation estimates 1725 peole with dementia in the local authority area. The CCG prevalence figure is calculated with a different methodology (CFAS 11) and indicates a prevalence of 1668. As the CCG has a national target to meet their figure will be used in the action plan.

#### 7.5 What does this mean for the strategy?

- The population of older people is increasing at a greater rate and we need to build resilience and skills into services to ensure they are supported.
- Our population is reporting levels of poor health, so we need to ensure we commission prevention and early intervention services that can support them at the earliest opportunity.
- We also need to consider the impact of caring on carers mental health and stress levels.

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.

#### **SECTION 8- REVIEW OF DEMENTIA SERVICES**

#### 8 References and Supporting Documentation

Document	Area of Impact on Strategy
Prime Ministers Challenge 2012 refreshed 2016	National picture evidence base
National survey – The Five Year Forward View	Evidence
NICE quality standards	Evidence
Health and prevention strategy Telford and Wrekin LA (2015)	Evidence Engagement
High quality care for all' (2008)	Evidence
NHS Constitution (2013)	Evidence
Seeing the person in the patient: the point of care review paper' (2008)	Evidence
The King's Fund developed a 'House of Care'	Model for strategy
http://toolkit.modem-dementia.org.uk/database/	Evidence

<sup>\*</sup>Dementia throughout this document is used to describe a symptom of a range of diseases ranging from Alzheimer's, vascular, Lewy body, Parkinson's and Fronto-temporal dementias.