

Priority: Dementia

Specific Focus for 2013/14:

- **Public Awareness of Memory Problems**
- **Information**
- **Early Identification and Diagnosis**
- **End of Life**

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Sponsor: Dr Mike Innes, Chair, Telford & Wrekin Clinical Commissioning Group

1. Integration

What services are currently commissioned and on what basis? Who are the key partners? What partnership arrangements/governance is place? Is there any informal service provision (e.g. self help groups)

A wide range of services are commissioned in Telford & Wrekin to support a person's journey with dementia and that of their family carers. This includes, health, social care, Voluntary and wider community support services. Please click on the following link to view the Telford & Wrekin Dementia Pathway <http://www.telford.nhs.uk/Telford-and-Wrekin-CCG/Services/Dementia1/>

Services have been commissioned based on national evidence and best-practice, derived predominantly from the National Institute for Clinical Excellence (NICE), the National Dementia Strategy, <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy> a local Joint Strategic Needs Assessment, the Prime Minister's Challenge on Dementia <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia> and local patient and service user experience, although, other resources have been used, as appropriate. Plans for service development and improvement have been driven and implemented by a Joint Telford & Wrekin Dementia Strategy (2009 – 2013) and a Multi-Agency Carers' Strategy. Please follow this link to view the respective strategies and action plans: <http://www.telford.nhs.uk/Telford-and-Wrekin-CCG/Services/Dementia1/>

Key partners in the identification, treatment, support and good quality care of people with dementia include;

- South Staffordshire and Shropshire Healthcare NHS Foundation Trust [South Staffordshire and Shropshire Healthcare Foundation Trust](#).
- Alzheimer's Society [Alzheimer's Society](#)
- British Red Cross [Red Cross](#)
- Age UK [Age UK](#)
- Carers' Centre [Carers Centre](#)
- Shropshire Community Health NHS Trust www.shropscommunityhealth.nhs.uk
- Telford & Wrekin Council [Telford and Wrekin Council MyLife](#)
- Shropshire and Telford Hospitals Trust [Shropshire and Telford Hospitals Trust](#)
- Shropshire Partners in Care www.spic.co.uk

Formal partnership arrangements are embedded within Contracts and Service Level Agreements and monitored through standard contract monitoring processes.

A pan-Shropshire, Telford & Wrekin, multi-agency group, (Health Economy Steering Group for Dementia) is the responsible group for implementing best practice in service improvements and is accountable to the Health and Well-being Board. This group meets bi-monthly. To view the Terms of Reference for this meeting, please visit: <http://www.telford.nhs.uk/Telford-and-Wrekin-CCG/Services/Dementia1/>. In addition, a Telford & Wrekin Dementia Provider Forum, meets twice-yearly, to ensure integration across the Dementia Pathway, whilst seeking to continuously drive quality standards and efficiencies, by working in partnership to deliver a seamless journey for people with dementia and their family carers.

There is a developing infrastructure of informal care and support being developed in Telford & Wrekin through our commitment to Dementia Friendly Communities. The Dementia Advisor Service, [Dementia Adviser Service](#) provides information about community-based support services and the newly published Telford & Wrekin Dementia Service Directory also contains information and signposting to self-help and other low-level support services, which includes information about the following:

- Telford Carers' support group
- Newport support group
- T42 (Wellington) support and activity group
- Singing for the brain group.

Please follow this link to view the on-line Dementia Services Directory [Telford and Wrekin Council MyLife](#).

2. Financial Sustainability

What is spent by each partner? Is the current level of spend sustainable or is the investment at risk? Are any savings required against this budget in 2013/14?

Except in the case of specifically defined dementia services, aligned to contract values, there is still ambiguity about resource deployment and activity levels, across health and social care. This is because it is difficult to quantify with any certainty the resources allocated specifically to dementia by the Clinical Commissioning Group and Telford & Wrekin Council, by service type, by age, and sometimes by geography. For example, many services do not routinely collect diagnoses for coding purposes, therefore it is not possible to separate 'older peoples' services from, say, dementia services. Where diagnoses are recorded it is not uncommon for the primary diagnosis for admission to be recorded, (e.g. the broken leg/hip), but not the secondary one which may be the reason for the delayed discharge, (e.g. dementia). Similarly, services, contracts and performance measures are not always aligned and so it is often not possible to compare like with like. Services overlap geographic boundaries differently, some include Staffordshire or Shropshire with Telford and Wrekin and others are Telford-specific. This coupled with variable access criteria, hours of operation, differing funding and contract cycles, make capturing finance data incredibly complex and challenging. However, from existing available data in the Joint Strategic Needs Assessment of Dementia (2009), it was estimated that health and social care in Telford & Wrekin spent in excess of £10.5 million a year on dementia services. For more detailed information, please see: <http://www.telford.nhs.uk/Telford-and-Wrekin-CCG/Services/Dementia1/>

Risks

The annual cost of care for each person with dementia is higher than the median salary in the UK, and is higher than the annual cost of care for a person with cancer and cardiovascular disease (stroke and heart disease) combined. The costs of providing dementia care are largely those required to provide support and care for activities of daily life, rather than medical treatments, so the costs associated with it, are predominantly social care. However, poor coordination of health and social care services, leads to avoidable hospital admissions, prolonged length of stay as a hospital inpatient and increased need for residential care. Therefore, there is significant financial risk, relating to demographic increase and inappropriate crisis and use of unscheduled care.

This pressure, coupled with inadequate investment aligned with raising prevalence, will widen the gap of unmet need.

With increased diagnosis rates and improved quality of care, as the National Dementia Strategy and NICE/SCIE guidelines are implemented; cost savings may be possible within several years. In the meantime, implementation is likely to add to the total cost of care.

3. Equity

How has current provision been designed to meet the differing needs from across the community? Are there any known equity issues apparent? e.g. inequalities in the provision uptake or outcomes for services?

The Dementia Joint Strategic Needs Assessment, (2009) considered the needs of a range of people with dementia, which included:

- Younger people with dementia - Numbers are relatively small in Telford & Wrekin rising from 44 estimated cases in 2009, to 51 cases in 2019. Small-scale services currently exist.
- People with learning disabilities - People with Down's syndrome are at high risk of developing dementia at a younger age; however, the Deep Dive analysis suggests that numbers in Telford & Wrekin will remain small, rising from 6 in 2009, to 7 in 2019. Commissioners continue to investigate good practice in models of care and local alternatives.
- People with alcohol-related dementia - Work is planned by Commissioners to define the level of need in Telford & Wrekin.
- People with other mental health problems (e.g. depression). The service re-design model for early intervention in dementia will address functional mental health issues such as depression and anxiety.
- People on low incomes and in poverty - The Older Adults' Strategy, (which includes Dementia) prioritises assisting people to access benefits and entitlements and Commissioners currently purchase specialist support from Age UK, Shropshire Telford & Wrekin.
http://www.telford.gov.uk/downloads/file/2686/older_adults_strategy_refreshed_2010-2014
- Minority ethnic groups – Age UK, Shropshire Telford and Wrekin is commissioned to provide a BME Neighbourhood Contact Officer, who has received Dementia training. Wider connectivity occurs throughout health promotion and social care, to ensure engagement and access to services.
- People living in isolated rural areas – Age UK, Shropshire Telford and Wrekin provides a Dementia Neighbourhood Contact Officer, to identify people at risk of social isolation and support them in accessing mainstream and other services.
- Disabled people - Commissioners continue to lead on the transformation of rehabilitation and reablement services, which will provide access and support for people with dementia.

4. Accessibility

What are the barriers to accessing services currently provided? Are the reasons for 'non-use' understood?

It is well understood both from national benchmarking and local understanding that dementia is under-diagnosed in Telford & Wrekin. Lack of diagnosis is a large barrier to access to dementia services.

The stigma associated with dementia can lead to reluctance to address the possibility of an individual having dementia and to professional groups giving lower priority to the development of the skills needed to identify and care for people with dementia. Sometimes, wrongly, people attribute the symptoms of dementia to an inevitable part of the ageing process. There is a view shared by some professionals and members of the public that little can be done to assist people with dementia, (*Alzheimer's Society (2008) Worried about your memory?*). This leads to failure to recognise and refer people early in the illness, creating problems later, as individuals present for the first time when in a crisis.

The work-stream around public awareness of memory problems will support the early identification and diagnosis priority because it is well evidenced that as a result of improved awareness, people will report symptoms earlier to their GP, which is the gateway to a formal diagnosis.

5. Quality

What are the key performance measures for this priority? How is the service currently performing? Do we understand why the service is performing at the current level?

Key performance Indicators (National and Local) are embedded in local contract agreements with individual Providers of services and monitored and reviewed on a regular basis.

Suggested key performance milestones for this priority work-streams include;

1) Public Awareness of Memory Problems

This is linked to the early identification and diagnosis performance milestones. (See below)

A base-line understanding of stigma and barriers to accessing diagnosis will be investigated by Race and Fairness Telford, (RAFT) in a distinct project, which will feed into this priority work-stream.

In addition, public awareness is best improved by a targeted and clear campaign. As part of this work-stream, we will identify five or less features that typify early dementia and advertise these intensely, whilst measuring the before and after effect.

2) Information

Promoting choice

Quality statement in the 2010 quality standard on dementia

5 Decision making

3 Written and verbal information

Quality statement in the 2013 quality standard on supporting people to live well with dementia

2 Choice and control in decisions

4 Leisure activities of interest and choice

9 Independent advocacy

3) Early Identification and Diagnosis

Current performance:

In 2012, the number of people on the General Practice Quality Outcomes Framework Dementia Register with a diagnosis of dementia was 693. In line with predicted local prevalence, the estimated number of people with dementia (diagnosed and undiagnosed) in 2012 was 1784. The percentage of people with a diagnosis of dementia in 2012 was therefore, 39.3%. It is therefore estimated that 1,071 people were without a diagnosis in 2012. This position puts Telford & Wrekin, 149th worst performing CCGs out of a total of 178.

However, it is also one of the PCTs/CCGs showing the most improvement, demonstrating a 3.7% increase in diagnosis rates for 2010-11^[2].

Milestone Target:

To increase diagnosis rates by 7% year-on year for the next 5 years.

4) End of Life

Quality statement in the 2013 quality standard on supporting people to live well with dementia

1 Discussing concerns about possible dementia

Palliative and end-of-life care

Quality statement in the 2010 quality standard on dementia

5 Decision making

9 Palliative care needs

^[2] Improvement ranking of 29 (1=most improved, 163=least), Alzheimer's Society, *PCT dementia prevalence and diagnosis rates*

A local performance indicator could be developed linked to family experience of the death of their loved-one with dementia as part of this priority work-stream.

As part of this priority work-stream, health and social care will work in partnership to define and agree appropriate quality metrics to evidence the impact of these agreed actions.

Is current service provision based on best practice or other evidence of effectiveness? Please list the relevant NCIE guidance/national guidelines etc

Current service provision has been developed in-line with clinical evidence and best practice, including but not limited to:

NICE <http://pathways.nice.org.uk/pathways/dementia>,

NICE Guidance CG42 (Dementia: Supporting people with dementia and their carers in health and social care) <http://publications.nice.org.uk/dementia-cg42>

NICE Dementia Quality Standard (QS1) <http://publications.nice.org.uk/dementia-quality-standard-qs1> This covers care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings.

NICE Dementia Quality Standard (QS 30) <http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-gs30> This quality standard covers supporting people to live well with dementia. It applies to all social care settings and services working with and caring for people with dementia.

These quality standards, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following frameworks:

- [The Adult Social Care Outcomes Framework 2013–14](#)
- [The NHS Outcomes Framework 2013–14](#)
- [Public Health Outcomes Framework for England 2013–16](#)

Quality standards support the role of [HealthWatch](#) as a consumer champion.
www.healthwatchtelfordandwrekin.org.uk

For a comprehensive up-date of progress against implementation of the Commissioning Framework for Dementia please visit <http://www.telford.nhs.uk/Telford-and-Wrekin-CCG/Services/Dementia1/>

As part of this priority work-stream the Commissioning Framework will be up-dated by March 2014, which will include a list of achievements against the priority areas.

6. Engagement & Positive Experience

What are service users' views on current provision? How have service users' views been used to inform current provision?

In 2009, the Telford & Wrekin Senior Citizens' Forum, in partnership with the Alzheimer's Society interviewed 87 carers of people with dementia culminating in the report; Now You See Me, Now --- ---'. Though the report did highlight some good practice and positive experiences, it largely eluded to a disaggregated system of 'hit and miss' support and inconsistent delivery of good quality of care.

Services under contract regularly carry-out service user and patient satisfaction surveys as part of their contractual obligations. In some cases, this is undertaken under the banner of a quality standard. In 2011, the South Staffordshire and Shropshire, NHS Healthcare Foundation Trust received an 'excellent' rating for the Shropshire, Telford & Wrekin Memory Service, with Accreditation by the Royal College of Psychiatrists for example.

More recently, patient and service user representation is captured in the Health Economy Steering Group for Dementia and Admiral Nurse Steering Group, which influences service re-design, development and drives service improvements. For example, patient and carer input has been pivotal to the design and implementation of the General Hospital Dementia Pathway, which strives to improve quality of care by a 'care-bundle' approach and minimising ward transfers.

Further more, ad hoc consultation events have been undertaken to influence local commissioning plans, including but not limited to;

- Consultation events via the Mental Health Pathway Development Group
- Consultation events as part of the Dementia Deep Dive/Joint Strategic Needs Assessment
- Millbrook Day Centre Service Review & Questionnaire
- Community Service Reviews
- Review of the Older Adults' Strategy through the Older Peoples' Partnership Board
- Consultation on the Falls and Bone Health Strategy (including carers of people with dementia) through the Falls Prevention Network
- Consultation on the Rehabilitation and Re-ablement Strategy (including carers of people with dementia).

7. Early Intervention and Prevention

What provision is in place to reduce future demand for this service/intervention?

Please describe the preventative or early intervention approach being adopted and the rationale?

Up to 50 % of cases of dementia may have a vascular component, giving an option of prevention by promoting better cerebro-vascular health. Current health promotion for diet, lifestyle and health checks are therefore likely to have a positive impact, though the full extent of this impact is not yet known. *The National Dementia Strategy* suggests that even the possibility that these activities may help the overall impact of the campaigns, makes them worth pursuing.

Furthermore, there is an evolving evidence base around activities which slow the progression of cognitive decline and therefore, there is an opportunity to link this aspect of prevention across other Health and Wellbeing Board Priority work-streams, as well as to work more closely with Public Health in the exploration and commissioning of specific initiatives which support these outcomes.

Given the ageing demographic in Telford & Wrekin, dementia prevalence will increase significantly over the next 20 years and therefore, there will be an increase in demand on services. However, failure to diagnose early can lead to individuals in crisis presenting late and therefore needing to access services that are more intensive and costly than would otherwise have been required and which reduce their quality of life unnecessarily. Therefore, identifying, diagnosing and treating people, where appropriate will ensure both clinical and cost effectiveness. *Banerjee and Wittenberg, Clinical and cost effectiveness of services for early diagnosis and intervention in dementia, International Journal of Geriatric Psychiatry (2009).*

Telford & Wrekin Clinical Commissioning Group (CCG) is currently implementing a Primary Care Pathway, with the intention of achieving early detection of people with memory problems. Furthermore, the CCG commissions a Primary Care Liaison Nurse to support early identification of memory problems, whilst regularly reviewing and supporting people with Mild Cognitive Impairment. A range of service providers, such as the Alzheimer's Society Dementia Advisor and Age UK Dementia Contact Officer is also commissioned to raise awareness of dementia in the community and signpost to appropriate services, including the GP for an initial assessment.

Other target-driven incentives relating to early identification of dementia include the National Commissioning for Quality and Innovation (CQUIN) plan for hospitals to identify people with dementia, visit [Shropshire and Telford Hospitals Trust](http://www.shropshireandwrekinhospitals.nhs.uk) to find out more. Furthermore, training has recently been delivered by the South Staffordshire and Shropshire Healthcare Foundation Trust in support of the NHS Health Check programme which will mean that from April 2013, people aged 65 to 74 will be given information on dementia and Memory Services. The intention is to raise awareness of dementia and highlight the relationship between the risk factors for CVD and dementia. For more information visit: <http://www.nhshealthcheck.nhs.uk/>

8. Safeguarding

How does current provision, ensure the safety of its most vulnerable clients?

All commissioned services are obligated, under contractual agreement to follow the policies and agreements written in the Telford & Wrekin Multi-Agency Adult Protection Policy. For further information, please visit http://www.telford.gov.uk/downloads/731/protection_of_vulnerable_adults

9. What difference/added value can the HWB make to this priority in 13/14 and how?

- Connect priorities across Health and Wellbeing Board work-streams for universal 'quick-wins' e.g. CVD and Dementia.
- Champion Dementia as a strategic priority across organisational and professional boundaries.
- To advocate for prioritisation of resources inline with expected prevalence rates.
- To advocate for prioritisation of training for the health, social care and Voluntary sector workforce, in contact with people with dementia, to improve professional awareness of the condition and the giving of high-quality information, care and support.
- To raise potential risks around disaggregation of joint-commissioning in-light of expectations around delivery and to identify appropriate clinical and non-clinical colleagues to work collaboratively within identified priority areas.
- To support the timely refreshment of the Joint Strategic Needs Assessment for people with Dementia.
- To consider developing a refreshed, multi-agency Dementia Strategy.