Living Well with Dementia
in Stoke-on-Trent – Joint Dementia Strategy 2015-19
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In Stoke-on-Trent, we have been working with our partners to improve services and support for people living with dementia and their carers for a number of years and as a result have seen great improvements in our diagnosis rates and the services available to support people with dementia and their carers.

However it is recognised that there is still much to be done. We know that dementia is a condition that still carries a great deal of stigma and fear which can often prevent people from seeking the help and advice they need. It also is a condition that is affecting more and more people each year with many people living with dementia reporting a loss in friendships and of becoming disconnected from their communities.

We also know that with access to the right support, treatment and care people can live well with dementia and this is the message that we want to spread loud and clear throughout the city!

We want Stoke-on-Trent to become a Dementia Friendly City, and to achieve this it means working together as a city. People with dementia and their carers must have a voice and be actively involved in the shaping and development of services and feel truly part of their communities.
For a number of years we have been working closely with our partners through the Dementia Steering Group and we want to thank all of our members for their on-going commitment, support and contributions. As a result we are proud to announce Stoke-on-Trent’s first local Dementia Strategy which is jointly presented by Stoke-on-Trent City Council and Stoke-on-Trent’s Clinical Commissioning Group. The strategy brings together years of hard work and sets out our shared vision and aspirations for improving dementia services within the city over the next 4 years.

The strategy builds on what people have told us is important to them and in March 2015 we held an event to share our vision and to see if we had identified the right priorities. We were so pleased to see so many people come together to share their experiences and discuss such an important issue and thank all those that attended for their contributions.

We learned from all our discussions that we are heading in the right direction, and the plan sounds good but people want to now see us take action. Working together with our partners we are committed to making this strategy a reality and to support people with dementia and their carers in Stoke-on-Trent to live well.
Introduction

The Dementia Strategy is jointly presented by Stoke-on-Trent City Council and Stoke-on-Trent Clinical Commissioning Group to reflect the local perspective within the wider regional and national context.

The term ‘Dementia’ is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. The most common type of dementia is Alzheimer’s disease with age being a main risk factor in developing dementia. Vascular dementia is the second most common form of dementia. A number of modifiable risk factors have also been identified as possible precursors to dementia including high blood pressure, smoking, excessive alcohol consumption and obesity.¹

It is a common condition currently affecting around 850,000 people in England, with this number predicted to increase by 40% in the next 12 years. The national cost of dementia is currently thought to be around £26 billion a year and is predicted to reach £35 billion in 2026.²

Although it is recognised that dementia can affect people of any age it is most common in older people, affecting 1 in 14 people over 65 and 1 in 6 people over 80. The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 to 95-and-over.³

How many people with dementia will need care and support is difficult to determine as personal circumstance and individual disease trajectory will have a bearing on specific requirements. It does however present a major and serious challenge to health and social care in terms of both the increasing numbers of people affected by dementia and the rising cost of providing a range of good quality services to enable people with dementia and their carers to live well.

This strategy is underpinned by the National Dementia Strategy and sets out the strategic direction for dementia services for people living in Stoke-on-Trent up to 2019 and beyond and will be used to inform and determine our commissioning intentions, service planning and development for each year for the life of the strategy.

Once new development plans have been agreed, the Stoke-on-Trent and North Staffordshire Dementia Steering Group, with multi-agency stakeholder representation, will maintain responsibility for overseeing local strategic delivery/action plans within a pre-designated reporting structure.

National and Local Guidance and Policy Context

National

Living Well with Dementia: A National Dementia Strategy’ was published by the Department of Health on 3 February 2009. The strategy had been under development since August 2007 and involved a wide range of ‘stakeholders’, including statutory and 3rd sector organisations, people with dementia and carers.

The strategy provided the national framework for improving the local development and delivery of services to people affected by dementia and the following three key areas were outlined for specific note:

• improved public and professional awareness
• access to earlier diagnosis
• support and empowering people to live well with dementia.

The strategy also identified 17 objectives4, the majority of which were to be implemented at local level, whilst ensuring that dementia pathways were closely aligned to other mental health services.

In 2012, the Prime Minister’s challenge on dementia was launched5 building on the work of the national strategy it outlined a number of commitments to deliver improvements in dementia care focusing on; driving improvements in health and social care, creating dementia friendly communities and better research.

In 2013 the Department of Health published; ‘A state of the nation report on dementia care and support in England’ which states that ‘we want a society where people with dementia can honestly say:

• I was diagnosed in a timely way.
• I know what I can do to help myself and who else can help me.
• Those around me and looking after me are well supported
• I get the treatment and support, best for my dementia and for my life.
• I feel included as part of society.
• I understand so I am able to make decisions.
• I am treated with dignity and respect.
• I am confident my end of life wishes will be respected. I can expect a good death.
• I know how to participate in research6.

The report outlines the known support and research available for people with dementia and the progress being made across England to deliver improvements and identified 10 priority areas for action which includes a focus on prevention, diagnosis and support, a need for high quality, compassionate care, empowering people to have greater personal control and the development of Dementia Friendly Communities7.

4 See Appendix 1 for further details  5 Prime Minister’s challenge on Dementia (2012) - Delivering major improvements in Dementia care and research by 2015
6 Department of Health, 2013, A state of the nation report on Dementia care and support in England’ 7 See Appendix 1 for further detail
In addition to the drive to transform dementia services, in recent years there has been continued focus across all health and social care services on supporting people’s choice and to develop and deliver services that are responsive and personalised to the needs of the individual.

A key policy document that cuts across all health and social care issues, is the White Paper ‘Our Health, Our Care, Our Say’ (2006) which set out a new direction for the whole health and social care system. With a strong emphasis placed on changing the way services were delivered, in particular by shifting the resources to support preventative services, delivering care closer to home and through the introduction of direct payments and personal budgets.

In addition, ‘Putting People First’, published in 2007, set out changes to social care services across all client groups - local authorities, working in close partnership with the local NHS, other statutory agencies, voluntary, private and independent sector providers, users and carers and the wider local community. The changes would create a new, high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carers.

This approach promotes outcomes which would ensure people are supported to:
- live independently
- stay healthy and recover quickly from illness
- exercise maximum control over their own life
- participate as active and equal citizens, both economically and socially
- have the best possible quality of life, irrespective of illness or disability and retain maximum dignity and respect.

The Department of Health published the ‘Caring for our future: reforming care and support’ White Paper, which sets out the vision for care and support and outlines the changes that are needed to ensure that current and future care and support:
- focuses on wellbeing
- enables people to stay independent for as long as possible
- are of improved quality and easily accessible
- provides better information to help people make informed choices about their care
- gives people more control over their care
- provides support for carers

National and Local Guidance and Policy Context
The ‘White Paper’ also emphasises the need for joint working approaches and planning between health and social care to support people with complex needs.

Both of these policy documents stress the importance of empowering and supporting people to manage their own care, giving them as much control over their own lives as possible, and focusing on their social inclusion, mental and physical wellbeing and preventing them becoming unwell.

NICE Clinical Guideline 42: 2006 (amended 2011) ‘Dementia: Supporting people with dementia and their carers in health and social care’, makes recommendations for the identification, treatment and care of people with dementia and the support of carers. It also promotes the need for an integrated approach to service design and delivery for people with dementia and their carers and the need for joint planning to include local service users and carers in order to highlight and address problems specific to each locality.

The commissioning of local services to support people with dementia and their carers is emphasised within the government directive, ‘Everyone Counts: Planning for Patients 2013/2014 – Improving Outcomes for people, by enhancing the quality of life for people with long term conditions’, of which dementia is now included.

Under the ‘Care Act 2014’, there will be additional responsibilities placed on local authorities to improve individual’s independence and wellbeing. These include greater responsibility to:

- Promote individuals wellbeing
- Promote integration of health and social care services
- Provide or arrange preventative services which reduce, prevent or delay the need for care and support
- Provide information and advice relating to care and support available locally
- Promoting diversity and quality in provision of services
- Co-operate with partner organisations
- Carry out assessments where it appears that an adult may have needs for care and support.
- Adhere to new rights to support for carers, on an equivalent basis to the people they care for
- Adhere to a national eligibility threshold setting one national level at which needs are great enough to qualify for funded services
- Provide continuity of care for individuals moving between authorities
- Have transparent charging policies
Local Guidance

In 2008, Stoke-on-Trent published the Older People Mental Health, Stoke-on-Trent, Joint Strategy 2008-2013, this joint health and social care strategy incorporated plans for service development for people with dementia and their carers. This was supported in 2009, by the development of a local implementation/action plan, to deliver services against the objectives laid out in the National Dementia Strategy (see Appendix 1). This joint strategy now builds on work previously completed to remain up to date and in line with national guidance and also the following local priorities and guidance.

In 2010 consultation on the redesign of Adult and Older Peoples Mental Health Services commenced, the main aim was to promote the delivery of mental health care closer to home achieved by introducing radical change to the way mental health services are locally provided.

The future direction and transformation of adult social care services was defined in the city council’s policy framework ‘Achieving Personalised Services for Adult Social Care in Stoke-On-Trent’. It set out the key principles required of all care services, based on national and local consultations. These principles include the following:

- Local and accessible services: Care closer to home
- Preventative: Focused on early intervention and prevention
- Choice: People have genuine choice of provision
- Independence: Services which promote independence

In 2012 Stoke-on-Trent CCG launched its ‘Clear and Credible Plan 2013 -2016’ and more recently Staffordshire and Stoke-on-Trent Five Year Strategic Plan 2014 -19 which sets out the CCG’s commissioning strategy and identified dementia as a priority area including increasing diagnosis rates, early diagnosis and support to remain as independent as possible.

The Stoke-on-Trent Joint Carers Strategy 2014-2018 has been developed in partnership with the City Council, Stoke-on-Trent Clinical Commissioning Group (CCG) health, voluntary and community organisations. This provides a framework for a more holistic, integrated approach to supporting carers; many carers of people with dementia are older people themselves, who may have physical frailty and health conditions of their own.
The Better Care Fund (BCF)\(^9\) was announced in the governmental spending review of June 2013. The BCF will be a pooled budget\(^10\) between Stoke-on-Trent Clinical Commissioning Group (CCG) and the City Council from 2015/16. The purpose of the funding is to:

- Drive forward agendas for the integration of the commissioning and delivery of NHS and social care services to better meet the needs of vulnerable people.
- Ensure that services (especially those associated with pressures on the acute sector, and urgent care) are planned ‘end to end’, and operate in an efficient, coordinated and coherent way.
- ‘Protect’ elements of the whole system (specifically social care) in the context of significant financial challenges.

There are a number of national conditions set in the development and delivery of the BCF plan. These are:

- plans to be jointly agreed;
- protection for social care services; as part of agreed local plans
- 7-day working in health and social care to support patients being discharged and prevent unnecessary admissions at weekends;
- better data sharing between health and social care, based on the NHS number (it is recognised that progress on this issue will require the resolution of some Information Governance issues by the Department of Health);
- ensure a joint approach to assessments and care planning;
- ensure that, where funding is used for integrated packages of care, there will be an accountable professional;
- risk-sharing principles and contingency plans if targets are not met – including redeployment of the funding if local agreement is not reached; and agreement on the consequential impact of changes in the acute sector.

The Joint Health and Wellbeing Strategy for Stoke-on-Trent 2013 – 2016, developed in collaboration across all partners, identified dementia as a priority area in particular around diagnosis and post diagnosis care in sustaining independence and quality of life.

\(^9\) originally the Health and Social Care Integration Transformation Fund (ITF)  \(^10\) S75 NHS Act (2006)
What people in Stoke-on-Trent have told us

The strategy has been developed building upon feedback received from a number of consultations with people in Stoke-on-Trent specifically around dementia services and dementia related support.

People have told us they want to see:

- Evolving, personalised and flexible services
- More coordinated services/better partnership working
- Quality services that are monitored.
- Better information, and improved access to information and support
- Early diagnosis and referrals to happen quickly
- Communities to be dementia aware
- More services, better access and greater investment

Following its initial development, there was a public consultation on the strategy. In general, feedback was supportive of the priorities and key considerations and ideas were provided which will inform the strategic delivery plan. Appendix 2 provides further detail on the consultations and emerging themes, the key themes were as follows:

- **Awareness raising to change perceptions**
  
  People still feel that there is a great deal of stigma and misconceptions about dementia which can be a barrier to seeking help. People want to see greater information and awareness raising about dementia with a particular focus on:
  
  - Reaching harder to reach communities and minority groups
  - Positive messages of living well with dementia – ‘look at what you can do – not what you can’t’
  - Regular and increased coverage in the media including social media
  - Providing the facts about dementia and signs and symptoms to be aware of
• **Education and training** concerns were raised about whether the workforce is appropriately skilled to support people with dementia. Feedback raised education as important to developing Stoke as a Dementia Friendly Community.

• **Service provision** people want improved access to services that are person centred, flexible, age and culturally appropriate and are available when people need them. Support needs to be available for carers and people living with dementia and should include practical and emotional support (including peer support). Concerns were raised over capacity and investments and a need to invest in prevention and early intervention.

• **Information and advice** people want to be able to easily access information about dementia and services and support that is available. People want to know where they can go if they need help or advice.

• **Quality** concerns were raised about the quality of services and what measures were in place to ensure quality.

• **Engage/involve/empower people with dementia and their carers** Feedback asked for commissioners and service providers to listen to people living with dementia and their carers and learn from their experiences. People asked for greater involvement of people living with dementia and their carers in shaping and developing services and raising awareness.
Demographics

3.1 National Picture

50,000 people are currently thought to be living with dementia in the UK and this is a figure predicted to significantly rise in the years to come.\(^\text{11}\)

Older People living with dementia
People of all ages can be affected by dementia; however age is a risk factor. 95% of people living with dementia are over 65 years old which is often, referred to as late-onset. The prevalence continues to increase with age as two thirds of people living with late-onset dementia are over 80 years old. It is estimated that if all remains constant the number of people living with late onset dementia will increase by 164% in the next 38 years.\(^\text{12}\)

The report also highlighted that late onset dementia is more prevalent in women as in 2013 there were 506,430 compared to 267,072 men over 65 living with dementia.

It is also estimated that almost two thirds of people living with late-onset dementia are living within their communities (61.3%), with just over one third of people living in care homes (38.7%).\(^\text{14}\)

Younger People living with dementia
Early-onset or young-onset is used to describe the number of people living with dementia who are under 65 years old, and makes up about 5% of people known to be living with dementia in the UK (approximately 40,000 people). If all remains constant it is expected that people affected by early on-set will rise by 20% in the next 38 years.

Younger people with dementia may have different needs and issues to overcome than someone experiencing late-onset dementia. For example they may still be working and have dependents and are more likely to have a rarer form of dementia.\(^\text{15}\)

The Alzheimer’s Dementia UK report (2014) estimated the following severity levels for people living with late onset

- 55.4% are living with mild dementia
- 32.1% are living with moderate dementia
- 12.5% are living with severe dementia.\(^\text{13}\)

It is estimated based on current prevalence and if no action is taken by:

- 2025 there will be 1 million people living with Dementia in the UK
- 2051 there will be 2 million people living with Dementia in the UK

(Alzheimer’s Society 2014)

1 out of 20 people living with dementia are under the age of 65
(Alzheimer’s Society 2014)

Carers of people living with dementia
Recent evidence suggests that there are around 540,000 Carers supporting people living with dementia in England and it is estimated that one in three people will care for a person with dementia in their lifetime. Approximately ‘half of those caring are employed and it is estimated that 66,000 people have already cut their working hours to make time for caring while 50,000 have left work altogether’.  

People with a learning disability living with dementia
Dementia in people with learning disabilities is becoming more common. This is because:
- Dementia becomes more common as people get older and people with learning disabilities are living longer
- People with a learning disability are 5 times more likely to develop dementia as they get older compared to the general population.
- People with Down’s syndrome have a specific additional risk of developing dementia. For them, this often happens at ages from 35 to 45 onwards. [1]

The number of people in Stoke-on-Trent with a diagnosis of dementia and learning disability is low, and will increase over time but not significantly. The Stoke-on-Trent Joint Strategic Needs Assessment identified the following priorities to ensure that people with a learning disability/dementia and their carers have access to the right care and support with robust pathways in place to ensure that individuals receive ‘person centred’ coordinated care as their illness progresses and their needs change:

- To continue to work with current care providers to raise awareness of dementia/learning disability
- Wider workforce development including dementia training for learning disability staff, awareness of environmental factors within the home and identifying any specific training requirements
- Pathway development
- Timely advice, information and support

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During 2009, the Royal College of Psychiatrists published a report[3] quoting dementia prevalence rates for; people with Down’s syndrome and for people with a Learning Disability without Down’s syndrome. For people with Down’s Syndrome prevalence rates of the general population were:

<table>
<thead>
<tr>
<th>Age</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 - 39</td>
<td>less than 10%</td>
</tr>
<tr>
<td>40 - 49</td>
<td>10 - 25%</td>
</tr>
<tr>
<td>50 - 59</td>
<td>20 - 50%</td>
</tr>
<tr>
<td>60+</td>
<td>30 - 70%</td>
</tr>
</tbody>
</table>

Applied locally it is estimated that under 100 people are living in Stoke-on-Trent with Down Syndrome and dementia. In the population of people with a Learning Disability without Down’s Syndrome, the study found that:

- 12% of the population aged over 50 would have dementia – which would equate to 76 people in Stoke-on-Trent
- 20% of the population aged over 65 would have dementia – which would equate to 166 people in Stoke-on-Trent
3.2 Population and prevalence in Stoke-on-Trent

Based on the earlier national prevalence rates of 2007 it was estimated that the number of people with dementia living in Stoke-on-Trent in 2013 was approximately 2,800.\textsuperscript{17}

Table 1 shows the estimated number of people living with dementia in 2013 by gender and age and similarities can be seen with the national picture as the number of people living with dementia in Stoke-on-Trent increases with age, and a higher proportion of people living with late onset dementia are female.

Using the prevalence rates of 2007, it is projected that the number of people living with dementia in Stoke-on-Trent will have increased to 4009 by 2030 with over 98% of people being over the age of 65.\textsuperscript{18}

By applying the national estimates of people living with mild (55.4%), moderate (32.1%) and severe dementia (12.5%) locally to those people with late onset dementia living within Stoke-on-Trent it is estimated that 1504 people are living with mild dementia, 871 people are living with moderate dementia and 339 people are living with severe dementia.

It can also be estimated by applying the national projections locally\textsuperscript{19} that just over 1000 people living with late-onset dementia in Stoke-on-Trent are residing within care homes and that almost 1670 people are residing within the community.

Diagnosing dementia

While there has been increasing knowledge and understanding around the prevalence of dementia a key issue is the disparity between the numbers of people thought to be living with dementia and those that have received a diagnosis. Despite a great deal of progress made the State of the Nation report on dementia 2013 reported less than half of people thought to be living with dementia had received a diagnosis.

Table 1: Number of people in Stoke-on-Trent estimated to have Dementia in 2013

<table>
<thead>
<tr>
<th>Gender</th>
<th>AGE</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;65</td>
<td>65-69</td>
</tr>
<tr>
<td>Male</td>
<td>37</td>
<td>97</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
<td>66</td>
</tr>
<tr>
<td>Total</td>
<td>63</td>
<td>163</td>
</tr>
</tbody>
</table>

\textsuperscript{17} Figures passed on ONS Mid-Year Population projections of resident population for the relevant year, and Dementia prevalence rates taken from the Dementia UK report (2007). \textsuperscript{18} Figures from POPPI and PANBI using Alzheimer’s Society Dementia UK (2007) prevalence rates applied to ONS population projections. \textsuperscript{19} National estimated that 61.3% of people within the community, 37.8% within care homes
3.2 Population and prevalence in Stoke-on-Trent

A diagnosis of dementia enables people to access support and treatment to help them to live well with the condition, and improving diagnosis rates has been a key priority nationally for a number of years. A national target was set for Clinical Commissioning Groups to ensure that by March 2015 two thirds of people estimated to be living with dementia have received a diagnosis.

To assist Clinical Commissioning Groups the Dementia Prevalence Calculator was developed to estimate the expected number of people with dementia in a given population. It applies the dementia UK prevalence rates to estimated population figures.

Diagnosis rates for a particular area or population can then be calculated by comparing the difference between the expected numbers of people with dementia to the actual number of people on the populations GP Dementia Register.20

Diagnosis Rates in Stoke-on-Trent

Table 2 shows the improvement in diagnosis rates for Stoke-on-Trent from 2006/7 through to 2013/14. In addition a local target was set for 2014/2015 of 68.5% which has now been achieved21 and a target of 72% has been set for 2015/2016.

<table>
<thead>
<tr>
<th>Measure</th>
<th>06/07</th>
<th>07/08</th>
<th>08/09</th>
<th>09/10</th>
<th>10/11</th>
<th>11/12</th>
<th>12/13</th>
<th>13/14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual Number*</td>
<td>1,079</td>
<td>1,072</td>
<td>1,133</td>
<td>1,216</td>
<td>1,388</td>
<td>1,601</td>
<td>1,774</td>
<td>2,035</td>
</tr>
<tr>
<td>Expected Number**</td>
<td>2850</td>
<td>2861</td>
<td>2900</td>
<td>2903</td>
<td>2939</td>
<td>2956</td>
<td>3026</td>
<td>3095</td>
</tr>
<tr>
<td>Variance</td>
<td>1771</td>
<td>1789</td>
<td>1767</td>
<td>1687</td>
<td>1551</td>
<td>1355</td>
<td>1316</td>
<td>1060</td>
</tr>
<tr>
<td>Diagnosis Rate</td>
<td>37.9%</td>
<td>37.5%</td>
<td>39.1%</td>
<td>41.9%</td>
<td>47.2%</td>
<td>54.2%</td>
<td>56.5%</td>
<td>65.7%</td>
</tr>
</tbody>
</table>

*Actual number = the number of people held on the Stoke NHS GP Dementia Register

**Estimated number = the number of people registered with the Stoke NHS GPs predicted to have dementia (calculated using the dementia prevalence calculator).22

20 The GP Dementia register is held by GPs as part of the Quality and Outcomes Framework (QOF) process. 21 Figures for 14/15 will not be ratified until June 2015. 22 The estimated numbers of people with Dementia in Stoke-on-Trent by GP practice is greater because the GP boundaries cross the boundary to Staffordshire.
**Vision and Priority Areas for Action**

In Stoke-on-Trent we want people living with dementia and their carers to live in a city where they:

- Feel included in society
- Are empowered and able to make decisions about their future
- Are treated with dignity and respect and that people around them have an understanding and awareness of dementia
- Can access high quality, personalised care and support services
- Know they will be (were) diagnosed in a timely way
- Know where to go for the right, information advice and support

The Stoke-on-Trent Joint Dementia Strategy has been developed on behalf of the City Council and Clinical Commissioning Group (CCG) in partnership with health, voluntary and community organisations. This strategy, in line with the national strategy and local consultation and guidance, sets out our key priorities over the next four years and will inform the strategic planning, service delivery and commissioning of support for people with dementia and their carers living in Stoke-on-Trent

**Our Vision is:**

To create a dementia friendly community that helps to improve the quality of life for people with a diagnosis of dementia and their carers. We will ensure that people are supported to live well with dementia through working together with service users, carers and partner organisations to continue to deliver the National Strategy at a local level.

“A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.”

Stoke-on-Trent has been successful in its application to join the recognition process for Dementia Friendly Communities, which means as a city it is recognised that we are working towards becoming dementia friendly.

To help achieve this vision, the following key priority areas have been identified to:

- spread the message of ‘living well’ - Improve professional and public awareness of dementia
- Ensure timely diagnosis and appropriate support at diagnosis
- Enable people to live well with dementia through access to high quality personalised support

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23 Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England
Priority 1: Spread the message of ‘living well’

Improve professional and public awareness of dementia.

National strategy and guidance suggests an overall lack of both public and professional awareness of dementia and highlights the impact this can have on a person’s ability to live well with dementia. Misconceptions that ‘dementia is a natural part of ageing’ or ‘that nothing can be done’ can prevent people from seeking a diagnosis and the necessary help and support\textsuperscript{24}.

‘Dementia is the condition that people over the age of 55 fear most - more so than cancer or heart disease\textsuperscript{25} and there is a belief that society is not geared up to deal with the condition\textsuperscript{26}. Research shows that people living with dementia have reported feeling lonely, and a loss in friendships\textsuperscript{27} and while almost two-thirds of people living with dementia are within their communities a research study showed that less than half of their respondents felt part of their communities.\textsuperscript{28}

Whilst good progress has been made since the launch of the National Dementia Strategy and the Prime Ministers’ Challenge on Dementia, in May 2014 Public Health England in partnership with Alzheimer’s Society launched the Dementia Friends Campaign with the aim of reducing fear, improving public and professional understanding and awareness of dementia and creating a network of 1 million Dementia Friends by March 2015.

Progress to date
In support of the national campaign, partners across Stoke-on-Trent and North Staffordshire have joined together to launch a local awareness campaign which commenced during dementia awareness week in May 2014.

The Staffordshire and Stoke-on-Trent Dementia Action Alliance has been developed to enable local members of Dementia Action Alliance and interested parties to share best practice and lessons learned and to explore opportunities for Staffordshire and Stoke-on-Trent to become more dementia Friendly.

\textsuperscript{24} Department of Health, February 2009: Living well with Dementia: A National Dementia Strategy  
\textsuperscript{25} YouGov 2011 cited in Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England  
\textsuperscript{26} Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England  
\textsuperscript{27} Alzheimer’s Society 2013 cited in Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England  
\textsuperscript{28} Alzheimer’s Society, 2013, Building Dementia friendly communities: a priority for everyone,
**Next Steps**

In Stoke-on-Trent we want to create a community where people living with dementia and their carers are empowered, met with understanding and can honestly say that ‘they feel included as part of society’. We want to raise public understanding about dementia to reduce fear and encourage people to seek help and support and to ensure that professionals are also appropriately skilled and dementia aware.

We will:

- Raise awareness about dementia in communities including key organisations and businesses, ensuring that key messages around dementia are consistent, relevant, timely and positive.
- Raise awareness about the importance of prevention and early intervention, including self-help and lifestyle interventions to reduce vascular risk factors.
- Raise awareness about national and local developments in research and opportunities
- Support people living with dementia to have a voice within their communities and have an active role in the development of dementia friendly communities.
- Ensure plans focus on priorities identified locally.
- Develop the workforce within Stoke-on-Trent:
  - To create a workforce that is dementia aware.
  - To ensure that staff directly providing care and support services are fully skilled in providing the highest level of care and support to people with dementia and their carers.
  - To support health professionals to provide good information and advice to individuals, their carers and families.
  - To change the culture and ensure that all staff/organisations are confident and skilled in delivering ‘person centred’ care and support and raise the quality of care delivered through up skilling all staff and dementia care becoming a core competencies in their own roles.

Section 5 provides further detail on the workforce aspirations for social care and health service providers.
Priority 2: Timely Diagnosis and Support

For people to receive a diagnosis in the right way, at the right time, with access to the right support

Local and national strategy and consultation highlights the need for people with dementia to have access to a timely diagnosis and appropriate support. In 2013 it was estimated that less than half of people living with dementia in England had a formal diagnosis (or were known to specialist services)\(^\text{29}\). Furthermore the emphasis on a timely diagnosis is important as a diagnosis can often occur at times of crisis or when the dementia is in the later stages limiting a person’s ability to make important choices and can also lead to early admissions into long-term care that could have been avoided.\(^\text{30}\)

A timely diagnosis is key to enabling people with dementia and their carers access to the best possible support, treatment and care\(^\text{31}\) and can empower people living with dementia to plan and make decisions about their own future.

The Department of Health is asking for Local NHS Commissioning Groups and local councils to work together to ensure that by 2015 two-thirds of people with Dementia have a proper diagnosis and get appropriate support and a key requirement of the Care Act is also to provide or arrange preventative services which reduce, prevent or delay the need for care and support.

Progress to date

Diagnosis and support at diagnosis has been a key priority within Stoke-on-Trent for a number of years and Data Quality Facilitators have been introduced to work with GPs to ensure that dementia registers are accurate and up to date and to help identify where performance is lowest.

In addition, people who have received or are in the process of receiving a diagnosis of dementia can access the Dementia Advisory Service. The service acts as a first point of contact for information and signposting, helping people to navigate and access appropriate and local services including access to peer support networks. The service provides people with the support and information they need to ensure people know of their options, and can plan for the future.

Year-on-year diagnosis rate targets have been set by the CCG and for 2014/15 this was set as 68.5% which exceeds the national target of two thirds. It has been confirmed that at the time of writing this target how now been achieved.

\(^{29}\) Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England  
\(^{30}\) Department of Health, February 2009: Living well with Dementia: A National Dementia Strategy  
\(^{31}\) Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England
Next Steps
Within Stoke-on-Trent we want to improve the quality of life for people with dementia by ensuring that people have access to the right information and advice and support to empower people to make informed decisions regarding their future. We want people in Stoke-on-Trent to be able to honestly say that they were ‘diagnosed in a timely way’ and have access to the most appropriate treatment and support. By reviewing and re-designing our Memory Services and through monitoring and evaluating our support services our priorities are to ensure that:

• diagnosis rates continue to increase a diagnosis is made within a timely manner and is diagnosed well by compassionate and appropriately skilled staff
• people have access to the appropriate support at diagnosis (including access to relevant information, advice, care and support)
• diagnosis rates are consistent across the city, with lower performing areas targeted for improvement
Priority 3: Enable people to Live Well with Dementia

Access to high quality, personalised support for both the person with dementia and their carers

It is recognised that with access to the right information, treatment, support and care people can live well with dementia.

With almost two-thirds of people living within their communities’ access to personalised appropriate community support services is vital to enable people to live well within their communities and remain as independent as possible. Evidence suggests that while people wish to remain in their own homes, all too often crisis situations arise which can result in avoidable or early admissions to hospital or long-term care due to a lack of appropriate support within the community.32

When in hospital people with dementia are reported to stay there longer33 and it is recognised a person’s symptoms may be amplified due to their environment and people may feel too unwell and low to return home and opt for long-term care which could have been avoided.

Existing Services/Progress to Date

Within Stoke-on-Trent there are specialist reablement/ intermediate care34 services available for people with dementia living within their community and approaching a crisis point or who are in hospital and are ready to be discharged. The service provides access to a multi-disciplinary team of professionals who can provide assessment and therapy support to help a person regain the skills and confidence they need to be able to return home or remain at home for longer. The services also provide a secure, supportive environment for people to make important decisions about the next stage in their lives and enable information and advice to be given to families and carers about the various options and support available.

For people with dementia and their carers who require on-going support there is also a wide range of services to support people throughout the whole pathway of living with a diagnosis of dementia. Appendix 3 provides more detail about support available. People who have concerns about Alzheimer’s disease or about any other form of dementia, are advised to contact the Alzheimer’s Society National Dementia Helpline on 0300 222 112235. The helpline can provide information, support, guidance and signposting to other appropriate organisations.

Re-design of dementia services

In June 2014 Stoke-on-Trent City Council’s Cabinet approved plans to establish a specialist joint health and social care dementia service at Marrow House by summer 2015. The service will offer bed based and community reablement services for people with dementia who require differing levels of support within the community, building upon the services which are currently being delivered from Abbots House and expanding the range of facilities and services available.

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32 Alzheimer’s Society (2011), Support, Stay, Save cited in Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England
33 Department of Health, November 2013: Dementia: A state of the nation report on Dementia care and support in England
34 Reablement is defined as “A way of helping you remain independent, by giving you the opportunity to relearn or regain some of the skills for daily living that may have been lost as a result of illness, accident or disability… Your council may offer a reablement service for a limited period in your own home that includes personal care, help with activities of daily living, and practical tasks around the home” SCIE, Think Local at Personal, Jargon Buster.
35 The Helpline is usually open from 9am to 5pm Monday to Friday, and Saturday and Sunday 10am - 4pm
Through further developments in integrated approaches to dementia care, and a move to more flexible working arrangements the re-design intends to provide more coordinated services, improve current reablement services and improve access to information, advice and support.

Ultimately, the specialist joint service at Marrow House aims to enable people with dementia and their carers to live well with dementia through improved access to:

- Specialist information, support and advice, ensuring that the right information and support is easily available throughout their journey with dementia
- A multi-disciplinary assessment of their needs in an appropriate setting
- Specialist bed-based and community reablement/therapy services to enable a person to be as independent as possible and where possible to return or remain within their own home
- A range of specialist professional services in one place
- Access to a choice of short break services across the city (that can offer planned stays).
- Early and timely intervention to help reduce occurrence of crisis situations that can lead to early and avoidable admissions into long-term care.

**Next steps**

Both nationally and locally people have told us they want access to coordinated, personalised services that will support not only the person with dementia but also the people that care for them. They have told us that access to clear information and advice and knowing where to go for help is really important. People also want services they can trust in, delivered by skilled people who understand about dementia. Through the re-design of dementia services and through our future commissioning intentions our priorities are to improve access to:

- Specialist reablement services for people with dementia
- Peer support groups
- Information and advice
- Services delivered by an effective workforce who are dementia aware or dementia skilled as appropriate
- Support for younger people living with dementia
- Support for people from minority groups living with dementia
- Community based services following an episode of illness
- Excellent end of life services
- Social work support and assessment
- Advocacy
- Assistive Technology

We are committed to engaging with people with dementia and their carers to enable them to inform and influence the support and services commissioned within Stoke-on-Trent.

A key priority will be to work with partners including carers, people living with dementia, providers and commissioners to develop robust contract monitoring to ensure that services are meeting needs and are of the highest quality.
The key development considerations for staff working with older people with mental health needs/ dementia largely reflect the strategic moves for social care more generally. The demographic pressure and increasing prevalence of dementia will hasten the need to move towards models of care that promote choice, increase independence and reduce or delay dependence on statutory services. Whilst currently a reablement service operates for people with dementia involving social care and health staff, the demand on this service, along with the need for appropriate exit maintenance services, will undoubtedly increase and it is vitally important that these services are equipped in understanding the best practice approaches key to the delivery of care to service users with cognition and capacity issues. In addition it is important that generic care services have a better understanding of the issues and the experiences faced by service users and carers.

Often this lack of awareness leads to exclusion from services. It has long been recognised that the attitudes, skills and knowledge of staff working with people with dementia have the potential to influence the person’s well-being, quality of life and function.

A key component will be an increased use of person centred/outcome based assessment and care planning, perhaps more widely used in younger person’s services but key to people who need to have their needs understood in terms of their own biographical history. Assisting staff in further developing their skills and knowledge ensuring an individualised, person-centred approach, where the whole range of needs is addressed, rather than simply the perceived problems.

Similarly there is a low uptake of direct payments/ individual budgets but recent health studies/conferences are stressing the need for this approach to be embraced as personal assistants may well provide the opportunity for a more consistent and familiar care delivery for the future.

Staff need to be skilled and training available in the non–pharmacological approaches to caring for people with dementia especially in residential care and nursing homes, day opportunities and community settings. There is also a national campaign to reduce the use of antipsychotic prescribing.

An informed and effective workforce for people with dementia.

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34 Reablement is defined as “A way of helping you remain independent, by giving you the opportunity to relearn or regain some of the skills for daily living that may have been lost as a result of illness, accident or disability… Your council may offer a reablement service for a limited period in your own home that includes personal care, help with activities of daily living, and practical tasks around the home” SCIE, Think Local at Personal, Jargon Buster. 35 The Helpline is usually open from 9am to 5pm Monday to Friday, and Saturday and Sunday 10am - 4pm.
It is well recognised that end of life care for people with dementia is an area in need of development\(^38\). Whilst some people with dementia receive excellent end of life care there are many that don’t receive appropriate care and support. At the end of their lives, many people with dementia are denied a death where their dignity and comfort is paramount and families/carers can feel unsupported or uninvolved.

Dementia care is an area frequently highlighted as needing development\(^39\) so as a health and social care economy we need to ensure that health and social care workforce are appropriately trained and competent with regards to the ‘Skills for Health End of Life Competencies’\(^40\) and ‘National Occupational Standards’ including communication skills, assessment and care planning, advanced care planning and symptom management as they apply to end of life care. This will also involve assessment of education and training needs of organisations and the general workforce to ensure that staff are equipped with the skills, training and knowledge in end of life care for people with dementia.

There are a number of key points about the workforce that stand out both nationally and locally including:

- The social care workforce is growing in size and is predicted to grow to enable it to meet the increased demand, this however presents wider issues relating to the difficulties that are arising both locally and nationally around the recruitment and retention of care staff.
- The majority of the workforce is employed in the independent/private and voluntary sector.

We need to ensure that we have ‘An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia’\(^41\)

Our vision is to improve the quality of life for people with a diagnosis of dementia and their carers and that people are supported to live well with dementia through ensuring that we have a confident, supported and well equipped workforce who will deliver truly person centred dementia care and support that:

- Individuals dignity and care is respected at all times
- People have maximum choice and control of their lives
- Independence is maintained where possible

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\(^{38}\) Sampson, 2006  \(^{39}\) CHAI, 2006  \(^{40}\) SFH 2009  \(^{41}\) (Objective 13 National Dementia Strategy).
The Dementia Steering Group provides the local steer for commissioning and development of services against the National Dementia Strategy. The aims and objectives of the group are to draw together all parties across health and social care provision including statutory, voluntary agencies, independent sector and users of services to implement the national and local dementia strategy with the aim of improving the well-being of those who have been affected by a diagnosis of dementia.

Following the publication of the National Dementia Strategy in 2009, Stoke-on-Trent Commissioners developed a Dementia Action and Implementation Plan for Stoke-on-Trent which outlines actions against each objective of the national strategy and how these would be delivered locally.

This document will be replaced by a strategic delivery plan which will be subject to annual review to reflect the delivery of the local strategy and any consultations/engagement/feedback.
Dementia Care Pathway

The diagram below shows the process a person can expect to follow when being referred to the Memory Clinics within Stoke-on-Trent. Appendix 4 provides a written summary of the process including more information on each stage of the pathway.

TIMESCALES

- Referral triage and appointment made for memory clinic within 4 to 6 weeks
- Diagnosis appointment made 2-3 months following initial assessment by secondary care (following initial assessment further tests may be required prior to diagnosis appointment).
- Assess response to treatment within 4 weeks
  - On-going monitoring – 6 months post 3 month review and thereafter.
Appendices

Appendix 1
National Dementia Strategy and The State of the Nation Further Information

Appendix 2
Local Consultation

Appendix 3
Service Tiers and Support

Appendix 4
Stoke-on-Trent Dementia Care Pathway

Appendix 5
Stages of dementia and support and skills required for the workforce
National Dementia Strategy: Objectives

Objective 1: Improving public and professional awareness and understanding of dementia. Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

Objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

Objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

Objective 5: Development of structured peer support and learning networks. The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

Objective 6: Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

Objective 7: Implementing the Carers’ Strategy. Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers’ Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.
Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people’s mental health teams to work in general hospitals.

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

Objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

Objective 13: An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

Objective 14: A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this strategy and set out in Annex 1.

Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers. Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

Objective 16: A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.
Objective 17: Effective national and regional support for implementation of the strategy. Appropriate national and regional support to be available to advise and assist local implementation of the strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

Department of Health: State of the Nation Report in 2013 the Department of Health published; ‘A state of the nation report on dementia care and support in England’ which states that ‘we want a society where people with dementia can honestly say:

- I was diagnosed in a timely way.
- I know what I can do to help myself and who else can help me.
- Those around me and looking after me are well supported
- I get the treatment and support, best for my dementia and for my life.
- I feel included as part of society.
- I understand so I am able to make decisions.
- I am treated with dignity and respect.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know how to participate in research.\(^2\)

The report outlines the known support and research available for people with dementia and the progress being made across England to deliver improvements and identified the following 10 priority areas for action:-

- **Prevention**: because the choices we make affect our risk of developing vascular dementia, we need to support people to make healthy choices to help them to avoid getting the condition.
- **Diagnosis and support after diagnosis**: Local NHS Commissioning Groups and local councils need to work together to ensure that, by 2015 two thirds of people with dementia have a proper diagnosis and get appropriate support.
- **High quality, compassionate care everywhere**: We need to give people with dementia and their carers care and support that is flexible, appropriate, and timely and provided by skilled staff whether at home, in hospital or a care home.
- **Greater personal control**: We need to enable people with dementia and their carers to exert control over their care and over their lives throughout all stages of their dementia.
- **Cutting inappropriate medication**: NHS and social care organisations must continue to reduce the inappropriate prescribing of antipsychotic medication for people with dementia.

\(^2\) Department of Health, 2013, A state of the nation report on Dementia care and support in England
• **End of life care:** Health and care professionals must be made aware of the alternatives to dying in hospital. Everyone with dementia and their families should have ‘planning ahead’ conversations with their doctor. End of Life care should be excellent with every person treated with dignity and respect.

• **Dementia education and training:** All NHS and Social Care staff should be aware of the signs of dementia and how best to support people with the condition, their families and carers.

• **Dementia Friendly Communities:** We need to create a dementia friendly society. We urge national businesses to become dementia friendly and to encourage their local branches to take this forward in their communities. We ask everyone to become a dementia friend so that more people know how they can help to support people with dementia and their families.

• **Research:** We need more dementia research and more people taking part in clinical trials. We ask those who fund research to strive ever harder to get the most from the excellent ideas, people and resources this country has to offer.

• **Better data and evidence:** We call on national health and care organisations – such as NHS England, Public Health England, Health Education England, the Care Quality Commission and the Health and Social Care Information Centre – to work with academic and research communities, the voluntary sector, industry and central government to improve the availability and quality of data on dementia care and support.
From September 2013-January 2014 a 120 day consultation was conducted around plans to re-design dementia services directly provided by the local authority and CCG. The consultation involved contacting families affected by the proposed changes and also partner organisations. Face-to-face meetings were also held with a number of voluntary sector groups.

From May - July 2014, EngAGE conducted consultation around dementia related support in Stoke-on-Trent at the June Fifty+ Forum event which approximately 50 people attended and also through the EngAGE outreach worker who visited 7 community groups, reaching an additional 206 people. The emerging themes from these consultations have been highlighted below and used to inform the strategy and priority areas for action.

**Emerging Themes**

**More services, better access and greater investment** – people told us they want better access to services such as short breaks/respite and day opportunities, and support specifically for carers including access to training. It was also identified that there was a need for services for younger people living with dementia.

**Evolving services** – people told us that it was important for services to be personalised, flexible with people’s changing needs and expectations and that are available at all stages of a person’s journey with dementia.

**More coordinated services** – people expressed a need for better partnership working between the different organisations that fund and provide support and services for people. All too often services are fragmented and difficult to navigate. People also expressed a need for services to be affordable.

**Quality services** – people want to see improvements in quality and to be assured that services are being monitored.

**Better information, and improved access to information and support** – people need support to navigate information and to know what support is available and from where. While there is information available it can be hard to know where to start and where the best place is to go for help with concerns over obtaining the ‘correct’ information.

**Speedy diagnosis** – people expressed a need for an early diagnosis and for referrals happening quickly. People mentioned the need for dementia specialists and ‘easier access to the memory clinic, although there was some confusion in perceptions of the Memory Clinic and what exactly it offers’ (Dementia Related Support, EngAGE: May-July 2014)

**Communities to be dementia aware** – people explained that ‘the whole community needs to be dementia aware and better informed about dementia, through all available media’.
Appendix 3
Service Tiers and Support

**Tier 4**
- Hospital Care
- Hospital/Care Home Avoidance
- Time limited intensive outreach

**Tier 3**
- Early Intervention through Outreach
- Community Support and Enablement

**Tier 1 and 2**
- Integration with Social Care
- Consultation and Advice
- Information and Training

**General Population**
- Lifestyle choices – Citizenship
**Tier 4 Severe Dementia**
- Multiple and complex needs.
- High risks.
- Loss of daily living skills, reasoning and communication, memory, physical frailty and vulnerability.
- Unable to maintain independence despite high intensity community support.

**Tier 3 Moderate Dementia**
- Not feeling safe.
- Significant issues relating to communication, memory, money, housing, transport and daily living skills.
- Need intensive support to maintain independence.
- Lack of effective social networks and physical well-being.

**Tier 1 and 2 Mild Dementia**
- Isolation, lack of confidence and close relationships.
- Issues relating to money, housing, transport and work.
- Some confusion and memory loss.
- Limited diagnosis.
- Stigma, discrimination and isolation.
- Lack of information, diagnosis and help seeking.
## Existing services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Supports Service Tiers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Services</td>
<td>Assessment, Diagnosis, Treatment, Review and Follow up</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Community Mental Health Teams</td>
<td>The community mental health teams for older people provide assessment, treatment, care management and review in the community. These include people who may have a variety of problems including anxiety, depression, dementia and other mental health illnesses of old age.</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Community Outreach Team</td>
<td>High intensive care management to prevent unnecessary hospital admissions and facilitate early discharge</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Vascular Wellbeing Service [Stoke only]</td>
<td>Supports early detection of VCI/MCI through screening and assessment of people of all ages presenting with memory issues in primary care</td>
<td>1 &amp; 2</td>
</tr>
<tr>
<td>Rapid, Assessment, Interface and Discharge Team [RAID]</td>
<td>Rapid mental health assessment, clinical intervention for patients and training and support to staff in the UHNS</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Stay at Home Team Service</td>
<td>Supported discharge and admission avoidance service for older people with dementia or mental health conditions. Referrals are through a number of routes including calling free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you.</td>
<td>1, 2, &amp; 3</td>
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37
## Existing services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Supports Service Tiers</th>
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</thead>
<tbody>
<tr>
<td>Dementia Advisory Service</td>
<td>Advisory, information and support services for people diagnosed with dementia</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Dementia Advocacy</td>
<td>Independent advocacy support for people with dementia</td>
<td>1, 2, 3 &amp; 4</td>
</tr>
<tr>
<td>Carers Training</td>
<td>Dementia awareness training, information advice and guidance for carers of people with dementia</td>
<td>1, 2, 3 &amp; 4</td>
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</tbody>
</table>
| Telecare                 | Telecare (also known as Assistive Technology) is the use of equipment around the home to help people stay safe and remain independent. This could be through a range of different types of equipment, such as:  
  • a pendant that you press if you need help (perhaps after falling over, or because you feel unwell)  
  • a smoke detector linked to a monitoring station, so someone will phone the fire service straight away  
  • a bogus caller button next to your front door - if you are concerned about a person who comes to your door, you can press and talk to someone immediately  
  • sensors to turn on the lights if you get out of bed at night, so you do not trip over anything in the dark  
You will need to call free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you | 1, 2, 3 & 4 |
**Service** | **Description** | **Supports Service Tiers**
---|---|---
Day Opportunities | Stoke-on-Trent City Council commission services with a number of providers who provide a range of day opportunities across the city including 1-2-1, community based and centre based services. Referrals for the services are via a social care assessment. You will need to call free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you. | 1, 2, 3 & 4
Domiciliary Care Providers | Provide care at home on a 1:1 basis to assist with managing personal care routines, nutritional needs, maintaining levels of independence and care. Stoke-on-Trent City Council commission services with a number of domiciliary care providers; referrals for the services are via a social care assessment. You will need to call free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you. | 1, 2, 3 & 4
Emergency Carers Scheme | Immediate support for the cared person if the person’s normal carer is unavailable for any reason. It gives the carer access to assistance 24 hours a day; 7 days a week Joining the scheme: • It is free to join • It is open to those carers who have had either a joint community assessment or a separate carers assessment • The carer can register using a simple application form obtained from the city council Contact free phone 0800 561 0015 | 1, 2, 3 & 4
# Existing services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Supports Service Tiers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed based reablement-GP Support</td>
<td>Medical Cover to support residential assessment and reablement for older people with dementia or mental health conditions.</td>
<td>3 &amp; 4</td>
</tr>
<tr>
<td>Assessment and Therapy Service</td>
<td>Residential assessment and reablement for older people with dementia or mental health conditions</td>
<td>3 &amp; 4</td>
</tr>
<tr>
<td>Respite Service</td>
<td>Sometimes people need short term support, to give them and anyone looking after them a break. This could be because having problems managing at home because of a health problem, a disability or because of carer breakdown. We have 11 respite beds commissioned from three residential care providers within the city. If you would like to speak someone about respite, you can speak to your social worker if you already have one, or you can call free phone 0800 561 0015 where you can speak to a contact centre advisor.</td>
<td>3</td>
</tr>
<tr>
<td>Residential Homes</td>
<td>Offering 24 hour care within a Residential Home setting. Stoke-On-Trent City Council commission services with a number of nursing homes; referrals for the services are via a social care assessment. You will need to call free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you.</td>
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There are a number of specialist wards for people over the age of 65 who may experience a wide variety of mental health problems. These include:

Ward 4 for older people in the early stages of dementia such as Alzheimer’s Disease. This ward provides specialist assessment, diagnosis, support and treatment and is known as the Assessment Ward.

Ward 6 for older people who experience on-going behavioural and psychological problems associated with either dementia or other mental health problems. This is known as ‘Complex Needs’.

Ward 7 provides assessment of functional mental health problems such as anxiety, depression or psychosis. Who is eligible for this service?

Older people who develop mental health problems in old age.

There are 40 assessment beds for people with organic and functional mental health problems and 15 beds for patients with complex needs

Most people admitted to the assessment wards will have been assessed in the community by a member of the community mental health older person’s services. This assessment could have been in the persons own home or at an outpatient clinic.

For the complex needs ward, people will have already been assessed on the older person’s mental health assessment wards.

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<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Supports Service Tiers</th>
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<tr>
<td>In Patient Hospital Beds</td>
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## Existing services

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</tr>
</thead>
<tbody>
<tr>
<td>Care Home Liaison Service</td>
<td>Supporting care management, medication review and admission avoidance for people in residential and nursing homes</td>
<td>4</td>
</tr>
<tr>
<td>Nursing Homes</td>
<td>Offering Nursing Care in a residential setting/environment Stoke-On-Trent City Council commission services with a number of nursing homes; referrals for the services are via a social care assessment. You will need to call free phone 0800 561 0015 where you can speak to a trained contact centre advisor who will be able to help and advise you and start the assessment process off for you.</td>
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Appendix 4
Dementia Care Pathway

GP Responsibilities
Person presents at GP’s with history of one or more of the following:
- memory problems
- reduced reasoning skills
- reduced abilities to undertake everyday tasks
- behaviour changes
- Communication problems

In Learning Disabilities – professionals involved may suspect dementia. Learning Disability pathway will then be followed and people will be seen in clinic at Broom Street Hanley, Stoke-On-Trent by Dr Marian Seagar and her team.

GP will:
- Carry out an initial assessment of the presenting complaints
- Decide on appropriate baseline cognitive assessment e.g. MMSE or collateral history from family and carers
- Decide on appropriateness of a referral to secondary care after excluding treatable physical health problems

Routes of Referral
- Stoke-On-Trent GPs can refer to the Memory Service which is currently based at Abbots House, Abbey Hulton, Stoke-on-Trent and will relocate by 2016 to Marrow House, Forrister Street, Meir Hay, Stoke-on-Trent.
- Specialist Learning Disability Service – Referrals forwarded to Broom St, Hanley, Stoke-on-Trent, ST1 2EW. Tel 01782 425080

Responsibilities of Secondary Care
All referrals will be triaged by nominated duty professional and forwarded to the appropriate discipline (e.g. Learning Disabilities, Neuropsychiatry, and Older Person’s Mental Health Service). The referrer and referred person will be informed by the duty professional of where the referral has been sent and an appointment will be made for the person to be seen at the memory clinic or at home within 4-6 weeks (a maximum of 42 calendar days).

Initial Assessment for Older People’s Mental Health Services and Young Onset Dementia (no behavioural problems)

NB Specialist Learning Disability Service – individuals will follow the Learning Disabilities Pathway.

Referred patients will be seen at the memory clinic, or at home or within a community setting, as appropriate.

NOTE: Referrals from secondary care (UHNS) and community hospitals will be picked up by the RAID Team and outcome communicated to GP as standard practice.
Memory Service Assessment will include:

- History taking
  Include presenting complaint, vascular risks, current medication, active/past medical history, social history, activities of living, driving status, allergies, alcohol, substance misuse

- Cognitive screening
  Using appropriate tool e.g. MMSE, ACE-R, clock drawing

- ADL assessment
  Speak to family/carers or use functional screening tool e.g. BADL

- Mood assessment
  Perform appropriate assessment e.g. history/MSE or use of appropriate screening tool

- Behavioural assessment
  Behavioural history from family/carers or use of appropriate screening tool e.g. NPI

- Carer’s views sought
  Social history, risks identified e.g. self-neglect, isolation, carer support, driving. Carers are also given the opportunity to be seen alone, to clarify situation and to express any concerns regarding the person.

- Dementia Screening blood tests as appropriate
  Including FBC, U&Es, TFT, LFT, Vitamin. B12/folate

- Brain scan e.g. CT or MRI

- Referral to other agencies – if appropriate

Consider referral to Social Services if:

- Changes in social functioning – self neglect, social isolation.
- Carer requires support
- Respite care is required
- Day care/support is required
- Home care is required (assistance with personal care, preparation of meals)
- Aids and Adaptations
- Residential care
- Safeguarding issues

Consider referral to Occupational Therapy if:

- There has been deterioration in the skills of activities of daily living e.g. cooking, shopping.
- An assessment re home adaptations is required.
- Training regarding memory cues is required.
- Road safety.
- Safety in the home.
- Unable to maintain structured meaningful routines and lifestyle.
- Advice on promoting a positive environment

Consider referral to Speech and language Therapist if:

- Communication problems identified
Consider referrals to Community Psychiatric Nurse/Mental Health Day Hospital if:

- There is a need for psychological interventions e.g. CBT, supportive counselling.
- Behaviour changes- withdrawn, aggression, agitation
- Mood changes – depression, anger, anxiety, fear.
- Carer experiencing difficulties

Referrals to Psychiatrist if person experiencing:

- Delusions/hallucinations
- Severe and intractable behaviour problems (e.g. aggression, sexual disinhibition)
- Concurrent depressive illness
- Diagnosis

Urgent Referral:

- Risk of harm
- Risk of abuse (from self/others)

NB All referrals to other agencies should be considered at each review.

Diagnosis

Patient seen 2-3 months following initial assessment by secondary care

- Seen by Consultant.
- Results of investigations discussed with patient and carer
- Diagnosis given to patient/carer if appropriate
- Involvement of dementia advisor post-diagnosis

Alzheimer’s disease: People with a diagnosis of Alzheimer’s disease may be considered for treatment.

- In eligible patients an initial prescription for cholinesterase inhibitors will be given for 28 days. The GP will be informed in writing of the medication prescribed.
- Patient and carer will be asked to contact the memory service if they experience any significant or concerning adverse effects.

Information given to patient/carer

- Includes information on the diagnosed illness, treatment and side effects, driving, power of attorney, benefits, support groups etc.
- Information given to patient and carer on Dementia Advisory Service for support, advice and information (Dementia Advisors are present in Memory Clinics).

Mild Cognitive Impairment/Atypical presentation

Consider referring to neuropsychology for further assessment. This may involve more detailed cognitive assessment, neuro rehab/compensatory strategies or psychological therapy to address issues related to mood/anxiety/confidence about memory functioning and fear of dementia causing hypersensitivity to memory lapses.
**Vascular Dementia**

Discuss management of vascular risks, e.g. hypertension, diabetes, diet, exercise. Refer back to GP for monitoring of vascular risks. If presenting with behavioural/mood problems, or psychosis then referral to be made to the Older Persons Community Mental Health Team.

**Assess the patient’s response to treatment**

Four weeks following diagnosis assess response to treatment if treatment initiated:

- After 4 weeks on treatment the patient will attend the clinic, be reviewed at home or in a community setting, or contacted by phone as to how the medication has been tolerated.
- If there are no problems, the dose may be adjusted to a higher dose and a prescription for 3 months issued/posted.
- Where adverse side effects have been a significant problem, the Consultant may decide to offer an alternative medication in accordance with NICE guidance.

**Three month review**

Three months post assessing response to treatment:

- Assess response to increased dose of treatment, and whether medication is beneficial and to be continued.
- Undertake cognitive and functional assessments if deemed appropriate by the individual clinician.
- Reassess cognition using appropriate tools e.g. MMSE/clock drawing/Addenbrookes
- Reassess ADL or BPSD by talking to carers or using appropriate screening tools.

NB If the patient is to continue treatment, on-going prescribing responsibility transfers to the GP.

Consider referral to other agencies if required.

**On-going Monitoring**

Six months post three month review and six monthly thereafter as per Shared Care Protocol:

- Should the patient develop additional mental health problems they will have full access to the Community Mental Health Team at any time while under the care of the Memory Service.
- At each reassessment a decision will be made about the on-going benefit of the medication and advice given to the patient’s GP.
- Any decision to terminate medication should be made in conjunction with a nurse and medic and communicated in writing to the GP.
- Patients may continue to be reviewed at the clinic, even if not on treatment.
- Consider referral to other agencies if appropriate (see earlier criteria).
- Patients who are admitted to residential homes/nursing Homes – will continue to be reviewed if on anticholinesterase inhibitors. The Care Home Liaison team accept referral from care homes for patients presenting with challenging behaviour and other psychiatric needs.
Mild Cognitive Impairment/possible early Stage

In the first stages of dementia, the signs and symptoms of the disease may be subtle. Often, the early signs of dementia only become apparent when looking back in time. The earliest stage of dementia (actually, it is not even dementia, it could be considered pre-dementia) is called Mild Cognitive Impairment (MCI).

70% of those diagnosed with MCI will progress to dementia at some point. In MCI, changes in the person's brain have been happening for a long time, but the symptoms of the disease are just beginning to show. These problems, however, are not yet severe enough to affect the person’s daily function. If they do, it is considered dementia. A person with MCI may have some memory trouble and trouble finding words but they solve everyday problems and handle their own life affairs well. In the early stage of dementia, the person will begin to show symptoms noticeable to the people around them. In addition, the symptoms begin to interfere with daily activities. A person appears confused, and forgets about things that have just happened. They may not remember where they are, or what they did five minutes ago. Long-term memory is usually not much affected, and a person with dementia often talks about the past.

Concentration and decision-making become difficult, and mood changes are frequent. A previously happy person may become irritable or depressed over small things. Others may notice changes without understanding why.

SOT GP Guidelines

Impaired by loss of memory for recent events. Some variable disorientation in time and place. Some difficulty with complex problems. Engaged in some activities but not independently. More difficult tasks and hobbies abandoned. Needs some prompting.

UHNS

6 CIT 0-7 Inform GP of UHNS result on discharch.
**Moderate/Second Stage**

As dementia progresses, the symptoms first experienced in the early stages of the dementia generally worsen. The rate of decline is different for each person.

The second stage, known as moderate dementia, brings more obvious confusion, forgetfulness and mood changes. A person may become anxious and aggressive. They may wander restlessly around the house and get up during the night. They may search the streets for a place or person from the past. They may also become suspicious of carers. Personal safety can be an issue, especially for those who smoke or cook. Even simple things like dressing can become difficult. The pressure upon carers is enormous as it becomes increasingly difficult to leave someone with dementia on their own.

If the person has Alzheimer's Dementia, in the moderate stages almost all new information will be lost very quickly. The person may be severely impaired in solving problems and their social judgment is usually also impaired.

Hobbies that previously provided enjoyment may be abandoned

**UHNS**

6 CIT – 8 – 9 refer to medical team, inform GP on discharge advice repeat 6 CIT after 6 months

**Severe/Final Stage**

In the final stages of the illness, a great deal of help is needed (people tend to need 24 hour supervision). Long-term memory may still be strong, but often a person is unable to recognise those close to them, unable to talk properly, or understand what is said to them. Incontinence is common.

During the later stages, most people become increasingly frail and may be confined to a wheelchair and then to bed. This makes them especially vulnerable to infections such as pneumonia.

He or she may have lost the ability to eat or swallow. Their appetite may decline to the point that the person does not want to eat at all. The person may be agitated.

**UHNS**

6 CIT above 10 refer to RAID

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Information taken from: - Making a Difference in Dementia: Nursing Vision and Strategy, NHS Health Education, NHS Commissioning Board
All Health Care Professionals: Workforce Competencies for Dementia

All health care professionals contribute of the stages of the Dementia pathway to
• Achieve
• Improve
• And sustain better outcomes

So that all people with dementia, at all ages, are able to lead quality lives for longer.

Specialist support and advice may be required at any stage as a result of a person’s complex needs. This will be specific to some health care professionals and additional to the work that all health care professionals do

Dementia Awareness
All health care professionals to have an awareness of dementia:
• Basic training
• Making every contact count
• Able to support and signpost public health messages

E.g: District nurses, practice nurses, PHN, Care workers, Therapists - Physio, OT

Dementia Skilled
All providing nursing to people with dementia directly
• All nurses that have more regular and intense contact with people with dementia, providing specific interventions, care and services.
• They have an enhanced knowledge and are skilled in dementia care.

E.g: GP, consultant geriatrician, Mental health nurse, liaison nurse, community matron, care home nurse, hospital nurse

Dementia Specialists
Experts in the field of dementia care.
• Health care professional with an expert level of skill and knowledge/specialist role/dementia champions in the care, treatment and support of people with dementia, their carers and families.
• Their educative and consultative role aims to improve the delivery of dementia services delivering changes in practice.

E.g: Consultant Old Age Psychiatry Admiral nurse, dementia specialist nurse
All Health Care Professionals may contribute to the care of people with dementia and/or their families at any stage.

Maintaining wellbeing and living well with dementia should be seen through the continuum.

- Keeping well and awareness raising/reducing social stigma
- Early identification, diagnosis and support
- Maintaining well-being and living well with dementia
- Managing acute and complex conditions with dementia
- End of life and bereavement support
‘A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported and confident they can contribute to community life.’